

# Reducing the Growing Burden of Inflammatory Bowel Disease in New Zealand



## Authors:

Sherilee Kahui  
Suzanne Snively  
Mark Ternent



**Crohn's & Colitis New Zealand Charitable Trust**

P O Box 22280

Khandallah

Wellington 6441

[www.crohnsandcolitis.org.nz](http://www.crohnsandcolitis.org.nz)

ISBN Number: 978-0-473-40073-6

# Reducing the Growing Burden of Inflammatory Bowel Disease in New Zealand

## Authors

Sherilee Kahui  
Suzanne Snively  
Mark Ternent

November 2017



The [Crohn's & Colitis New Zealand Charitable Trust \(CCNZ\)](#) was established in early 2010 in a nationally coordinated way to respond to the needs of Crohn's and colitis patients across New Zealand. From that small but dedicated group of individuals, it has grown steadily, with Crohn's and colitis support groups now operating in thirteen regions throughout New Zealand, working collectively toward our goal, offering support through fellowship, education and participation in fundraising.

CCNZ wants to see better care provided for people with IBD. Targeting the following four areas would assist in achieving this:

1. Earlier diagnosis
2. Equitable access to healthcare specialists across all DHBs
3. Better and equitable access to effective healthcare treatments and interventions
4. Increased social connectedness for all patients and their families

As shown in this report, there is already sufficient evidence about the need for these areas to be addressed.

# Table of Contents

---

|   |    |
|---|----|
| Foreword.....   | 3  |
| Glossary .....  | 5  |
| Executive Summary .....                                       | 7  |
| Table of Figures.....   | 12 |
| Contributors to this Study .....                              | 13 |
| 1. Overview of the Conditions .....                           | 15 |
| 2. Epidemiology.....  | 19 |
| 3. Direct Costs.....  | 23 |
| 4. Indirect Costs.....  | 33 |
| 5. Quality of Life.....                                       | 39 |
| 6. Conclusions .....  | 45 |
| 7. Next Steps.....  | 51 |
| Appendix A – Epidemiology Methodology & Assumptions .....     | 55 |
| Appendix B – Direct Costs Methodology & Assumptions.....      | 58 |
| Appendix C – Indirect Costs Methodology & Assumptions.....    | 61 |
| Appendix D – CCNZ Survey Methodology & Selected Results ..... | 65 |
| Appendix E – References.....                                  | 66 |

## Foreword

---



**Brian Poole QSM, CCNZ Co-Chairman**

New Zealand has one of the highest rates of Inflammatory Bowel Disease (IBD) in the world and each year more and more people are being diagnosed.

An estimated **20,792<sup>1</sup> New Zealanders** have been diagnosed with IBD as at 31 December 2016, a prevalence that is comparable to that of Type 1 Diabetes. This is approximately **1 in 227** people. Numbers are increasing at an estimated rate of **5.6% annually**.

Unlike many modern diseases that are finding cures through lifestyle changes, this one is not so easily resolved. IBD is a difficult, lifelong and chronic autoimmune disease for which there is currently no cure, only careful management and a variable treatment path. The typical age of onset is 15-35 years old, making it as much a young persons' disease as an older persons' condition.

IBD carries a stigma associated with some of the often embarrassing, devastating effects of the disease. Despite the growing numbers of people affected, for those in the community who are unaffected it is largely an invisible condition. There is little public discussion and low public awareness. Thousands of New Zealanders, both young and old, have been suffering largely in silence as a result.

IBD is an impending health crisis for the country if left unchecked, with the actual cost of IBD far exceeding that of initial diagnosis and treatment. This study estimates the New Zealand IBD burden of disease was **\$245 million per annum** in December 2016.

Unsurprisingly to patient advocates, this report identifies the physical and associated psychosocial costs to the individual, including mental health consequences which are often due to the stigmatisation of those with the condition. It also identifies the broader social and economic costs to the country as a whole, especially in lost productivity and higher healthcare costs to government. The study looks at the baseline economic costs of IBD and the direct impact the disease has on work days lost to illness, increased rates of hospitalisation, and higher treatment costs (including for other conditions that IBD patients are at a higher risk of developing due to their condition).

This report also finds that IBD is generally poorly understood even by those in the medical community, including General Practitioners, District Health Boards and national health planners. Low levels of IBD-specific education, coupled with the lack of public awareness and the associated stigma, increases the time taken to identify and diagnose the disease in new patients. The standard of care really hasn't kept up with the number of cases diagnosed, and while there are pockets of good practice in parts of New Zealand, the standard of care is patchy and access is inequitable. Delayed diagnosis can often lead to more invasive, intensive and costly treatments being required. The study also finds inequitable and inconsistent access to specialist care for New Zealanders with IBD, particularly those living outside the geographic areas where specialists reside.

Crohn's & Colitis New Zealand (CCNZ) exists to bring visibility to this difficult, invisible condition. We provide support, advice, resources and information about Crohn's disease and ulcerative colitis to patients and their families. Our organisation includes individuals affected by Crohn's and colitis, and medical specialists who are active in the treatment of these chronic diseases.

---

<sup>1</sup> Estimate derived from several regional studies over period 2004 to 2016

We welcome this report and the findings of the study, and call for urgent action on IBD diagnosis, support and disease education in New Zealand. CCNZ strongly supports the recommendation to establish a National Care Working Group, with appropriate expertise and representation. We also endorse the implementation of an action plan – both immediate and longer term – which includes addressing the very patchy availability of data and overall lack of quantitative research into IBD in New Zealand, before it becomes a national health crisis.

A handwritten signature in blue ink that reads "Brian Poole". The signature is written in a cursive, slightly slanted style.

Brian Poole QSM  
CCNZ Co-Chairman, November 2017

## Glossary

---

|      |                                    |
|------|------------------------------------|
| CBT  | Cognitive Behavioural Therapy      |
| CCNZ | Crohn's & Colitis New Zealand      |
| CD   | Crohn's Disease                    |
| DHB  | District Health Board              |
| DRG  | Diagnosis-Related Group            |
| FTE  | Full-Time Equivalent               |
| GP   | General Practitioner               |
| HRC  | Health Research Council            |
| IBD  | Inflammatory Bowel Disease         |
| LTC  | Long-Term Condition                |
| NCD  | Non-Communicable Disease           |
| NZCP | New Zealand College of Pharmacists |
| PHO  | Primary Health Organisation        |
| TNF  | Tumour Necrosis Factor             |
| UC   | Ulcerative Colitis                 |

## Definitions

---

|                                      |   |   |
|--------------------------------------|---|---|
| <b>Adalimumab</b>                    | - | the anti-TNF $\alpha$ pharmaceutical (biologic) with the greatest uptake by those with IBD in New Zealand   |
| <b>5 Aminosalicylates (5-ASA)</b>    | - | medications used to suppress low-grade inflammation   |
| <b>Anti-TNFs (biologics)</b>         | - | a type of manufactured antibody that helps stop inflammation by targeting the TNF alpha protein (TNF $\alpha$ )   |
| <b>Cognitive Behavioural Therapy</b> | - | a psychotherapeutic treatment commonly used to help improve the quality of life of "in-need" IBD patients   |
| <b>DALY</b>                          | - | a Disability-Adjusted Life Year: a measure of overall disease burden, expressed as the number of years lost due to ill-health   |
| <b>Deadweight Loss</b>               | - | the cost of raising taxpayer revenue, loss of procurement and consumer surplus  |
| <b>Direct Costs</b>                  | - | an expense that can be traced directly to (or identified with) a specific cost  |
| <b>Economic Burden</b>               | - | analysis of the economic impact of ill health   |
| <b>Ileostomy</b>                     | - | where the loop of small intestine is brought out onto the surface of the skin through a surgical opening. Body waste then passes out of the ileostomy/stoma and is collected in an adhesive bag that attaches to the skin over the top of the stoma |
| <b>Incidence</b>                     | - | the number of people with a condition over a specific period of time  |
| <b>Indirect Costs</b>                | - | the impact of a condition, covering costs such as time off work   |
| <b>Infliximab</b>                    | - | an anti-TNF $\alpha$ pharmaceutical (biologic) approved and funded in New Zealand for IBD treatment   |
| <b>Mesalazine</b>                    | - | an aminosalicylate most used by those with IBD  |
| <b>Pharmac</b>                       | - | the New Zealand Government organisation mandated to decide the schedule of pharmaceuticals available through the public health system   |
| <b>Prevalence</b>                    | - | the proportion of people with a condition at a point in time, both now and pre-existing   |
| <b>QALY</b>                          | - | a Quality-Adjusted Life Year: a generic measure of disease burden, including both the quality and the quantity of life lived  |
| <b>Stoma</b>                         | - | an artificial opening made into a hollow organ, especially one on the surface of the body leading to the gut or trachea   |

# About the report

---

## Contributors

MoreMedia Enterprises was commissioned by CCNZ to analyse the economic impact of IBD in New Zealand based on a similar analysis done by PwC's Melbourne Office in 2013 for [Crohn's & Colitis Australia](#).

The work involved consultation with a stakeholder group involving gastroenterologists, nurses, patients and caregivers, as well as a desktop review of current literature, best practice and analysis of place-based studies.

## Project scope and limitations

This study has been carried out at a high level, examining desktop analysis. Primary research centred on a survey of members conducted by CCNZ in 2017 on behalf of this study, which provided many useful insights. Other primary research was restricted because of the limited data obtainable within the tight time frame of this study. The report cites many robust references; however, a degree of extrapolation or reference to other international studies needed to be undertaken in places.

## Structure

The report is structured to include:

1. An overview of IBD, its impacts and complications
2. Updated prevalence and incidence statistics for New Zealand
3. Identification of the direct costs associated with IBD
4. Indirect costs incurred by IBD
5. An outline of the non-financial costs that affect IBD patients and their families
6. Conclusions
7. Next steps

# Acknowledgements

---

The authors wish to acknowledge and thank all those who have generously provided their time, experience and expertise to contribute to this report. In particular we wish to thank the many patients who shared their personal experiences of living with IBD with us, and whose knowledge and insights have enriched this report. Special thanks also to the CCNZ IBD Workshop Members (listed on p.13), who have given so freely of their time and expertise. Finally, heartfelt thanks to Brian Poole, CCNZ Co-Chair and IBD patient, who recognised the pressing need for this study, and without whose leadership, drive and deep personal commitment to improving the lives of IBD patients it could not have been accomplished.

The authors are solely responsible for the views and findings set out in this report, and any errors or omissions.

This study was made possible through an unrestricted education grant by Janssen New Zealand.





# Executive Summary

---

## Overview

Inflammatory Bowel Disease (IBD) is an emerging global disease for which there is currently no cure. New Zealand has one of the world's highest rates, but to date there have been no detailed New Zealand-wide studies of IBD prevalence and incidence.

*Reducing the Growing Burden of Inflammatory Bowel Disease in New Zealand* commissioned by Crohn's & Colitis New Zealand Charitable Trust (CCNZ), is a first step towards an informed national discussion about the growing problem of IBD in New Zealand. In the absence of national data, the report has drawn on estimates and studies carried out over 16 years within specific DHB regions, as well as patient surveys, case studies and international data.

The report looks at the personal, social and economic consequences for the estimated 20,792 New Zealanders who have this devastating illness. It also looks at the cost of IBD to the country, estimated to be in the region of \$245 million annually.

The report finds that New Zealand lacks an effective, equitable, patient-centred approach to addressing the increasing burden of IBD, and one that also achieves the best value for public health spending and outcomes. It finds that diagnosis of IBD in New Zealand is slow, and that the number of New Zealanders with IBD symptoms may be higher than currently estimated. It notes that along with more timely diagnosis, earlier and more effective interventions could significantly lift the quality of life for IBD patients, and reduce the cost burden.

The report establishes a clear imperative for a comprehensive nationwide study of IBD prevalence, and an IBD National Care Working Group to address the shortcomings in diagnosis, treatment accessibility and standards of care identified in this report.

In commissioning this report, CCNZ hopes to increase awareness of the disease and its impacts, promote discussion about the level of understanding, care and support available to the growing number of IBD patients both young and old, and encourage a more evidence-based approach and action plan to address a critical unmet need in our community.

## What is IBD?

Crohn's disease (CD) and ulcerative colitis (UC) are known collectively as Inflammatory Bowel Disease (IBD). These are chronic, lifelong, currently incurable diseases that are unpredictable in diagnosis, disease course and treatment. Symptoms include abdominal pain, diarrhoea, rectal bleeding and weight loss, with significant variation in the severity and pattern of symptoms affecting each patient.

IBD is characterised by periods of remission punctuated by acute active flares. The relapsing and chronic nature of the disorder has broad and often profound impacts on a person's physical and psychosocial wellbeing<sup>2</sup> through ongoing debilitating symptoms, social stigma, reduction in ability to work, management of bathroom access issues, difficulty with physical intimacy, and loss of work, career and personal options.

IBD affects people of all ages, but is primarily a disease of young adults in the prime of their lives, with onset typically between the ages of 15-35 years.<sup>3</sup> People diagnosed with IBD therefore face a lifetime of illness, largely hidden from the outside world, as well as the side effects and risks of medication and surgical treatments.

---

<sup>2</sup> *Ibid.*

<sup>3</sup> Gearry, Poole, Rawlings, Worsfold, & Wyeth, 2010, p. 3

IBD is brought on by an abnormal response of the body's immune system. As with other autoimmune diseases, the exact cause of IBD remains unknown at present.<sup>4</sup>

## Prevalence and incidence

New Zealand has one of the highest rates of IBD (prevalence) in the world and each year more and more people are being diagnosed (incidence). There are currently an estimated 20,792<sup>5</sup> New Zealanders who have been diagnosed with IBD or 1 in 227 people.

Over the 12 years from 2004 to 2016, the number of people living with IBD (prevalence) is estimated to have increased by around 68%, or 5.6% per year.

IBD incidence is also growing steadily. Over the year to 31 December 2016, an estimated 1,796<sup>6</sup> additional cases were diagnosed. Over the 10 years from 2003 to 2013, the number of new IBD cases is estimated to have increased by around 81%. Indicatively, New Zealand will double its IBD patient population by 2026.

But current estimates are unlikely to present the full picture, as IBD can take weeks or even years to be diagnosed after symptoms first appear. There are also apparent inconsistencies with diagnosis based on geographic location of patients.

There is a clear imperative for a comprehensive nationwide study on IBD prevalence.

## Cost burden

The economic burden of IBD is shouldered by patients, their families, the healthcare system and wider New Zealand society. The most significant economic costs are from lost time in education and work as patients and family members seek diagnosis, undergo treatment and adjust to prescribed pharmaceuticals and life-style changes. These costs will continue to rise as the number of cases of IBD steadily increases.

National hospital admissions data for 2001-2013 showed 28,369 IBD admissions, with significant annual increases in the rate, particularly for CD patients, and a parallel increase in hospital costs. Anecdotal evidence from the patient community also points to the costs of frequent extra visits to GPs for IBD-related issues.

Additionally, the costs to patients and the national health budget of surgery, including potentially avoidable surgery caused by delayed diagnosis and unnecessarily lengthy treatment pathways, as well as outpatient services, emergency department presentations, mental health support, and medicines, has also increased.

International IBD studies have established a pattern of significantly increased mortality for Crohn's disease patients in particular, with associated costs to families and the healthcare system. For ulcerative colitis patients, with a lower mortality rate, overall healthcare costs have substantially increased, due to ongoing treatment required throughout their lifetimes.

## Indirect costs

This report also finds evidence that patients with IBD have significantly increased absenteeism and reduced workplace productivity due to their condition. The national cost of this is estimated to be \$86 million annually. Of New Zealand patients surveyed, 20% attributed absences from work of 20 or more days per year to IBD, with Australian analysis finding that 43% of IBD patients in paid employment had on average 7.2 lost work days each year due to IBD issues.

IBD patients also have impaired performance on the job due to their condition (presenteeism) costing an estimated \$52 million in lost productivity annually. Of patients surveyed, 57% reported that IBD negatively

---

<sup>4</sup> Crohn's & Colitis New Zealand, 2017

<sup>5</sup> Estimate derived from several regional studies over period 2004 to 2016

<sup>6</sup> Estimate derived from several regional studies over period 2003 to 2013

influenced their productivity levels on more than 10% of work days. Australian randomised clinical trials reported a mean reduction in overall workplace productivity due to IBD ranging from 34-48%.

Loss of employment, the need to reduce working hours, and the downgrading of employment status, also represent significant costs for many IBD patients. Other indirect costs to the country may include welfare and other support services, and lost tax revenue through future lost productivity.

Carers of school-age children afflicted with IBD report that these children miss an average of 20 or more days of school per year, as well as missing activities such as sport and school trips. The potential negative effects of these losses on future GDP have not been calculated but are likely to be substantial.

## Understanding and awareness

Patient survey data examined for this report, along with the observations of patient advocates, suggests that IBD is poorly understood among GPs and national health planners. In a recent survey, one in five patients reported their diagnosis took more than two years.

There is also low public awareness of this disease, despite the number affected being akin to the number of New Zealanders with Type 1 diabetes. Low levels of public understanding and inadequate medical education on IBD have significant and often traumatic consequences for affected individuals. These negative effects are also likely to have an increasingly visible impact on the country's healthcare budget and strategy as the numbers affected continue to rise.

## Impact on quality of life

IBD has a major impact on the quality of life of patients and caregivers, and influences their future outlook, intimate relationships, recreation and sporting activities as well as their earning potential.

One third of parents who have children with IBD see a major impact on their child's education, and around half see an effect on their child's overall future, mental wellbeing and ability to participate in sport and recreation.

This study found that access to quality IBD care in New Zealand is inequitable. District Health Board (DHB) locations have varying degrees of IBD expertise, with the number of IBD nurses and gastroenterologists with a special interest in IBD seemingly based on where the individual professional happens to live rather than any correlation to DHB population<sup>7</sup>. The current reactive model of IBD management sees patients in many underserved regions of New Zealand only seeking help during an acute flare.

## Conclusions

The report finds that IBD prevalence and incidence has markedly increased in recent decades, the severity of the conditions has increased, and the onset of the disease is most prevalent in earlier ages of adulthood.

The following key findings require action:

- There is clear evidence that the current model of care for IBD patients is inadequate, inconsistent and inequitable.
- The annual cost to New Zealand of IBD is estimated to be \$245 million and growing.
- Particular concern exists around the lengthy diagnostic timeline and evident geographic inconsistencies stemming from a lack of specialist medical knowledge in regions outside of the main centres to enable earlier intervention.
- IBD is poorly understood by national health planners and this will have increasingly significant consequences as the number of IBD patients continues to rise.
- There is little public and media discussion around IBD due in part to the challenging nature of some symptoms of the disease.
- A pressing need exists for high quality research to construct a nationwide evidence base from which to develop a nationally consistent response to IBD care.

---

<sup>7</sup> Association of Salaried Medical Specialists, 2010, p. 43

The report provides a series of suggested next steps to address these issues.

## Next steps

### *Reducing the impact of IBD*

The impact of IBD on patients, their families and the healthcare system can be reduced through better management of the disease. A proactive care model requires a knowledgeable, multi-disciplinary, professional team engaging with a patient regularly and over the long term. It means treating the condition in a timely, more effective and patient-centred manner, and viewing IBD care through a biopsychosocial<sup>8</sup> lens.

The benefits of such an approach will include decreased hospitalisations and emergency department presentations, decreased need for surgery, reduced morbidity, improved quality of life and increased work productivity. In addition to these benefits it will mean more efficient screening for the cancers that IBD patients are at higher risk of developing, and will also facilitate safer monitoring of medication, both in terms of potential side-effects and compliance.

There is evidence from the Australian [2013 PricewaterhouseCoopers \(PwC\) BOD study](#) (based on an earlier study by [Access Economics](#)) that these benefits translate into substantial savings to the health care system. More effective IBD treatment adopted in South Australia demonstrates improved outcomes for patients, their families and communities, as well as cost savings. Other benefits include lower social costs, higher educational attainment and a stronger contribution to the economy.

Further research is required to inform recommendations of an optimal patient pathway, a national capability framework for IBD care programmes, and corresponding service requirements.

### *A plan for action*

This study has found sufficient evidence for some immediate actions, in particular steps that need to be taken to improve national access to care. These include:

#### *1. An IBD National Care Working Group*

- to address the implications of this study and the implementation of appropriate and accessible care nationwide. It should include members from:
- Colorectal Surgical Society of Australia and New Zealand
- Crohn's & Colitis New Zealand
- Dietitians NZ
- New Zealand College of Pharmacists
- New Zealand Nurses Organisation Gastroenterology Nurses' College
- New Zealand Paediatric Gastroenterology Clinical Network
- New Zealand Society of Gastroenterology
- Royal New Zealand College of General Practitioners
- Representatives from Obstetrics and Mental Health

#### *2. Research to develop guidelines for a New Zealand Standard of Care for IBD Patients*

- to improve the potential for earlier diagnosis and as a consequence earlier and more effective interventions. This work would form the basis of a care model and would aim to achieve the following:
- *construction of a nation-wide evidence base* from which to develop a nationally consistent response for the improvement of IBD care, including gaining a better understanding of the determinants of IBD resulting in earlier diagnosis

---

<sup>8</sup> Knowles & Mikocka-Walus, 2015

- *a clinical trial investigating the impact of the timing and use of pharmaceutical interventions*, using existing New Zealand databases of IBD patients
- *compilation of evidence to support an exercise to calculate DALYs and QALYs for IBD* as a basis for considering whether IBD be afforded the priority that is given by the Ministry of Health to other long-term conditions
- *specification of the pathways of care for IBD* that maximise patient wellbeing while reducing direct health care costs, indirect and economic costs.

It is recommended that funding in the form of a five-year grant be sought from the Health Research Council (HRC). The research aim outlined above is consistent with the HRC's priority to fund transactional and transformational research that has the potential to improve health outcomes and delivery of healthcare and to produce economic gains for New Zealand.<sup>9</sup>

### 3. *Information and communication*

- a communication plan to develop the knowledge base about IBD across DHBs and Primary Health Organisations (PHOs) to ensure early and accurate diagnosis of IBD followed by appropriate treatment
- a body of work to ensure that first responders, be they GPs, paediatricians, nurses or mental health counsellors, know enough to consider and initiate timely investigations to identify IBD in their patients, and
- information for primary care practitioners about who to approach for advice and where to send their patients for appropriate expert treatment, irrespective of where they practise in New Zealand.

---

<sup>9</sup> Health Research Council of New Zealand, 2017

## Table of Figures

|   |    |
|---|----|
| Figure 1: Estimated Prevalence by DHB as at 31 Dec 2016 .....   | 20 |
| Figure 2: IBD Population Growth Scenarios.....  | 22 |
| Figure 3: Estimated Prevalence Internationally .....  | 22 |
| Figure 4: IBD Admission Rates.....  | 23 |
| Figure 5: Annual Cost of Medical and Surgical Hospital Admissions and Therapeutic Infusions* for Individuals with IBD, July 2001 to June 2013 in 2015/16 NZ Dollars** ..... | 24 |
| Figure 6: Hospitalisations for IBD, 0-24 year olds, by age group, NZ 2000-2015.....   | 25 |
| Figure 7: Top Diagnosis-Related Groups: those which Most Drive Hospitalisation Cost... ..   | 25 |
| Figure 8: Traditional Approach for Treatment of IBD in New Zealand .....  | 26 |
| Figure 9: IBD Pharmaceutical Summary Type and Use for 2016 .....  | 28 |
| Figure 10: Cost of Mesalazine and Adalimumab .....  | 29 |
| Figure 11: Time from First Presentation to Diagnosis.....   | 30 |
| Figure 12: Estimated Employment-Related Indirect Cost of IBD Per Annum to NZ GDP..  | 34 |
| Figure 13: Days off work per year due to IBD .....  | 35 |
| Figure 14: Employment Status Change .....   | 36 |
| Figure 15: Impact IBD diagnosis has had on a patient's quality of life .....  | 40 |
| Figure 16: Impact IBD diagnosis has had on a child's quality of life .....  | 40 |
| Figure 17: Disease Management and Access to Care .....  | 41 |
| Figure 18: Satisfaction with the NZ Health Care System / Overall Effects.....   | 42 |
| Figure 19: Number of IBD-Related Surgeries per Person (Based on 207 respondents) ....   | 42 |
| Figure 20: Current Distribution of IBD Nurses .....   | 48 |
| Figure 21: Total of Known or Estimated Costs 2016.....  | 49 |
| Figure 22: Weighted Average NZ Prevalence, using 2 data points .....  | 56 |
| Figure 23: Estimated Prevalence - 2004 and 2016.....  | 56 |
| Figure 24: Estimated 2016 NZ Incidence .....  | 57 |
| Figure 25: IBD-Related Diagnosis Related Groups with Cost and Discharge Data .....  | 59 |
| Figure 26: Possible Savings from Introduction of Formal IBD Service .....   | 60 |
| Figure 27: Decrease in Productivity while at Work and Affected by IBD .....   | 62 |
| Figure 28: Percentage of Days where IBD Affects Productivity while at Work .....  | 62 |
| Figure 29: Impact IBD had on Change in Employment Status .....  | 63 |
| Figure 30: Estimated GDP Loss Reduction.....  | 64 |

# Contributors to this Study

---

## STEERING COMMITTEE CHAIR

Brian Poole, CCNZ Chair, CCNZ Trustee (Patient)

## PROJECT TEAM CCNZ IBD BOD STUDY

Suzanne Snively, Project Director (MD, MoreMedia Enterprises, Health Outcomes Economist)

Sherilee Kahui, Research Analyst and Writer (MoreMedia Enterprises)

Mark Ternent, Business Consultant and Quantitative Analyst (MD, G5 Consulting)

## WORKSHOP MEMBERS (Workshops Held 28 February 2017 / 3 April 2017) Wellington

Kerryn McIntosh-Watt, Solicitor (Patient)

Hannah Morton, PhD Student, Studying Vitamin D in relation to Crohn's disease

Dr Peter Murray (PHARMAC)

Charlotte Perkins, CCNZ Administrator

Henriette Rawlings, Statistics NZ (Parent of IBD Patient), Trustee CCNZ

Anna Scanlen, Evaluation and Research Consultant, (Patient)

Dr James Stanley, Bio-Statistician, University of Otago

Dr Richard Stein, Gastroenterologist, Trustee CCNZ

Matt Tyson, Therapeutic Group Manager for Gastroenterology, PHARMAC

Dr John Wyeth, Gastroenterologist/PHARMAC

## Palmerston North

Maria Berrett, Clinical Psychologist

## Waikato

Sarah Cook, IBD Clinical Nurse Specialist (CNS)

## Auckland

Maddie Shannon, Sociologist/ 2017 CCNZ IBD Survey of Burden of Disease (led the survey, analysis and report of the results)

## Christchurch

Professor Andrew Day, Paediatric Gastroenterologist

Professor Richard Geary, Gastroenterologist

## Dunedin

Christine Ho, IBD CNS (Clinical Nurse Specialist)

Professor Michael Schultz, Gastroenterologist (Otago Medical School, Dunedin)

Dana Smith, Nurse and IBD patient (Southern District Health Board)

## Nelson

Chris Budgen, Pharmacist

## OTHER CONTRIBUTORS

Patients, Parents, Nurses, Supporters at Camp Purple – January 2017

Francesca Manglaviti, CCA Crohn's & Colitis, Australia

Dr Richard Milne

Dr Jean Simpson

## Reviewers:

Professor Richard Geary Gastroenterologist

Russell I Heigh MD Mayo Clinic Arizona

## Proof Reader:

Maggie Jenns

**Administration:** Raewyn Irwin





# 1. Overview of the Conditions

---

Inflammatory Bowel Disease (IBD) is a group of systemic disorders that cause the intestines to become inflamed and ulcerated. It is brought on by an abnormal response of the body's immune system. It is unknown what determines this response. The main forms of IBD are Crohn's disease (CD) and ulcerative colitis (UC).

IBD is a lifelong, chronic disease, usually starting in early adulthood in otherwise healthy, active individuals. There is no cure for IBD – most patients require regular medications to manage this condition, even during periods of remission. Additional medications are needed during flare-ups. When this fails, surgery is often required.<sup>10</sup> IBD is largely unpredictable, with significant variation in the severity and pattern of symptoms affecting each patient. The relapsing and chronic nature of IBD impacts quality of life through ongoing debilitating symptoms, reduction in ability to work, social stigma, management of bathroom access issues, difficulty with physical intimacy, loss of leisure time and limited choices of career, travel and other personal options.

The impact of IBD on patients' quality of life is substantial due to early onset, a fluctuating disease course and the current lack of a cure<sup>11</sup> although international research continues, including into the role of the gut microbiome<sup>12</sup> and other factors. People with IBD therefore confront a lifetime of illness, largely hidden from the outside world, as well as the substantial side effects and associated risks of treatment. IBD can have a substantial impact on patients' mental health, with research indicating co-morbidity with both depression (15%) and anxiety (20%).<sup>13</sup>

Crohn's disease can affect any section of the digestive tract between the mouth and anus. CD manifests chiefly as gastrointestinal symptoms such as diarrhoea (with or without per rectal bleeding), abdominal pain and malnutrition.<sup>14</sup> These symptoms in turn can lead to anaemia, fatigue and weight loss. CD normally results in intensive medical therapy and (in some cases) repeated surgical resection.

While there are similarities in presentation to CD, ulcerative colitis is restricted to the large intestine and rectum. Although it can be 'cured' by surgical removal of the large intestine, this is an extreme option, with reduced quality of life.<sup>15</sup>

Both diseases are characterised by periods of remission punctuated by acute active flares. When experiencing a flare, IBD patients require near-continuous care to address their clinical needs and surgical treatment may be required to manage the associated complications. The severity and persistence of the symptoms, as well as the impacts of IBD therapies, have a profound impact on a person's physical, professional and psychosocial wellbeing. Extra-intestinal manifestations such as joint pain, arthritis, liver disease, skin and eye problems may also occur.<sup>16</sup>

Many of the drugs used to treat IBD have adverse side effects, with a failure rate of between 20% and 40%.<sup>17</sup> Strict patient compliance is needed for medications to be efficient and constant monitoring must be maintained to ensure that different medications are not interacting adversely.

Severe IBD has an increased risk of digestive and respiratory diseases, digestive cancers, lymphoma, osteoporosis and mortality.<sup>18</sup>

---

<sup>10</sup> Crohn's and Colitis Foundation of Canada, 2012, p. 7

<sup>11</sup> Johan Burisch *et al*, 2013, p. 323

<sup>12</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5473501/>

<sup>13</sup> Neuendorf, Harding, Stello, Hanes, & Wahbeh, 2016, p. 70

<sup>14</sup> Lopez, 2016, p. 2

<sup>15</sup> Pricewaterhouse Coopers, 2013, p. 2

<sup>16</sup> Forbes, 2013, p. 1

<sup>17</sup> Wyeth, 2017

<sup>18</sup> Forbes, 2013, p. iii

## Case Study 1: Adult with IBD

Up until October 2011, I led a really busy and full life – I had been to university, gained two undergraduate degrees and one postgraduate degree, worked for a global accounting firm, moved to government as a solicitor, started to move into management, got married, rode horses, went to the gym, socialised with friends, the list goes on. It is fair to say I lived life at 120%.

On 17 October 2011, I got sick. It started with a sore stomach and diarrhoea. Every evening I started to get chills all over my body and then the intense cramps started. At their worst, I had to sit on the toilet as well as vomit into a bucket because the cramping was so bad. I also developed painful welts on my arms and legs. Throughout this I tried to get to work each day. I worked until about 4pm then came home and went to bed. I didn't see my horse for weeks and could hardly interact with my husband. I literally worked, ate what I could and slept. I lost about 14kgs in three weeks.

My doctor sent me to a private gastroenterologist. I had a colonoscopy and was diagnosed with Crohn's disease. I was put on prednisone and Pentasa and started to feel better within 24 hours. The welts on my arms and legs also started to go away.

Over the next 18 months I continued to have flares which seemed to coincide with periods of stress in my life. I was placed onto Humira and azathioprine and things were OK. I realised that I needed to take time to rest more than I used to. I couldn't go to the gym early in the morning, work a long day then ride my horse at night. If I did this on a regular basis I would start to flare.

The worst flare I had involved a 10-day hospital stay with insane pain every time I went to the toilet. I had anal fissures. These eventually healed with IV steroids and a subsequent course of prednisone. Prednisone also has its fair share of side effects including finding it hard to sleep, and a swollen face (commonly known as "moon face"). There are a number of other side effects but I was lucky to avoid these.

In August 2013, I had intense pain in my perianal area. I subsequently had an MRI and it was determined that I had an abscess and possibly fistulas (tracks that run from an abscess). Between October 2013 and March 2015, I had nine surgical procedures done in an attempt to drain the abscess and try to heal the three fistulas I had. I also had continual infections and had to be on antibiotics for long periods of time.

In March 2015, I went to see my colorectal surgeon and we decided it was time for a temporary ileostomy. An ileostomy is where the loop of small intestine is brought out onto the surface of the skin through a surgical opening. Body waste then passes out of the ileostomy/stoma and collected in an adhesive bag that attaches to the skin over the top of the stoma.

The first month with my temporary ileostomy/stoma was harder than I ever expected. I had a number of leaks from the bag and had to continually have district nurses in to change them. I couldn't change it myself as I had a bridge in my stoma which had to stay in for a number of weeks to stop my intestine being absorbed back into my body. I felt like I no longer had any control over my life and felt like it was getting worse every day.

It was after a conversation with my Mum and her identifying that I sounded like I was getting depressed that I realised I needed to pull myself out of this or go and get help. Through determination and support I got to a point where I could leave the house and was ready to get back to work.

That was three years ago and I still have the stoma. I also still have a fistula which occasionally causes me problems and I have to take antibiotics. I have learnt to live a relatively full life with my stoma. I am far more aware of where toilets are if I need to change my bag. I am more aware of what I put into my body at what times to avoid situations where it is difficult to go to the toilet. I always carry a big handbag as that allows me to always have supplies to change my bag if necessary. Most importantly, I am more aware of the clothes I wear to ensure that they don't put any pressure on the bag causing it to leak.

I always said when I was diagnosed with IBD that it would not beat me and it hasn't, although at times I feel it has come very close!!



## 2. Epidemiology

---

### Overview

For reasons not yet clearly understood, IBD is largely a disease of the developed world. New Zealand Europeans are at a much higher risk of developing the disease than Māori or other Pacific Island ethnic groups.<sup>19</sup> Although detailed New Zealand-wide prevalence and incidence data for IBD are currently unavailable, several regional studies and estimates over the last 16 years have recorded or estimated prevalence and/or incidence in specific DHB jurisdictions across the country. Refer to Appendix A for the approach taken for the calculation of prevalence, incidence and projections and for the assumptions and data sources used to describe the epidemiology of IBD.

While the estimations for prevalence and incidence are given as specific figures, it is noted that the actual figures will be different and will fall within a range. Multiple methods could have been used to estimate those figures and that range, however all would rely on publications that are old, not as detailed as the original Gearry report, and from single geographic areas which even together cover only a small portion of New Zealand's population.

Nevertheless, from the studies reviewed, it is clear that both prevalence and incidence are increasing, and there is good evidence that the condition is underdiagnosed, and therefore the estimated prevalence of 20,792 could be understated.

### Prevalence

Prevalence is defined as being the proportion of people who have a particular disease at a point in time. It includes all cases, both new and pre-existing.<sup>20</sup>

As at 31 December 2016, the extrapolated prevalence of IBD in New Zealand is 20,792 cases or a prevalence of 4.4 cases per 1,000 people (one person in every 227, approximately). In addition to that, it is evident that a substantial number of people with IBD have yet to be diagnosed. A survey of people with IBD<sup>21</sup> indicates that IBD can take weeks and even years to be diagnosed, from the first appearance of IBD symptoms. This appears to differ geographically around New Zealand.

During the 12 years over which IBD prevalence data has been collected, prevalence has increased by approximately 68%. While better data would be needed to establish the true increase in prevalence, it is clear that the number of New Zealanders who are living with IBD is increasing, not just in absolute terms, but also as a percentage of the population.

Initial results of the first-ever nationwide study<sup>22</sup> on the prevalence of IBD on all patients in New Zealand under 16 years of age on June 30, 2015, were released in August 2017. The study was undertaken by the University of Otago, Christchurch. The data showed between 40 and 60 children per 100,000 in the South Island had a diagnosis of an IBD, while in the North Island the rate was between 10 and 20 children per 100,000. Researcher and paediatric gastroenterologist Professor Andrew Day said the difference between the two islands was not fully understood but could be due to variations in sunlight, and its impact on vitamin D levels. He said the findings warrant further investigation.<sup>23</sup>

There has not been a non-age-specific nationwide study on prevalence to date. Figure 1 uses the regional study data that is available and extrapolates it to DHB areas based on New Zealand census population distribution (not adjusted for age or ethnicity).

---

<sup>19</sup> Gearry *et al*, 2006, p. 580

<sup>20</sup> U. S. Department of Health and Human Services, 2017

<sup>21</sup> CCNZ Survey 2017

<sup>22</sup> Lopez *et al*, 2017 : Point Prevalence of Pediatric Inflammatory Bowel Disease in New Zealand in 2015: Initial Results from the PINZ Study <http://journals.lww.com/ibdjournal/pages/results.aspx?txtkeywords=new+zealand+children>

<sup>23</sup> <http://www.scoop.co.nz/stories/GE1709/S00113/first-study-of-inflammatory-bowel-disease-rates-in-kiwi-kids.htm>

Figure 1: Estimated Prevalence by DHB as at 31 Dec 2016

| DHB                                      | Est. diagnosed   |               |
|--|------------------|---------------|
|  | Pop. 2016        | Prevalence    |
| Auckland District Health Board           | 510,450          | 2,251         |
| Bay of Plenty District Health Board      | 226,530          | 999           |
| Canterbury District Health Board         | 543,820          | 2,398         |
| Capital and Coast District Health Board  | 307,250          | 1,355         |
| Counties Manukau District Health Board   | 541,080          | 2,386         |
| Hawkes Bay District Health Board         | 161,780          | 713           |
| Hutt Valley District Health Board        | 145,310          | 641           |
| Lakes District Health Board              | 105,170          | 464           |
| Mid Central District Health Board        | 174,340          | 769           |
| Nelson-Marlborough District Health Board | 147,210          | 649           |
| Northland District Health Board          | 170,560          | 752           |
| South Canterbury District Health Board   | 59,210           | 261           |
| Southern District Health Board           | 319,200          | 1,407         |
| Tairāwhiti District Health Board         | 47,680           | 210           |
| Taranaki District Health Board           | 118,110          | 521           |
| Waikato District Health Board            | 400,820          | 1,767         |
| Wairarapa District Health Board          | 43,890           | 194           |
| Waitemata District Health Board          | 597,510          | 2,635         |
| West Coast District Health Board         | 33,190           | 146           |
| Whanganui District Health Board          | 62,445           | 275           |
| <b>TOTALS</b>                            | <b>4,715,555</b> | <b>20,792</b> |

Source: Estimated prevalence, extrapolated by census DHB populations

Despite the growing population of people with IBD, the disease seems to be relatively unknown. This may be partly due to the embarrassment, and, therefore, taboo of talking about common symptoms, such as diarrhoea and incontinence.<sup>24</sup>

A comparison of IBD prevalence with better known conditions in New Zealand

|                          |  |
|--------------------------|--|
| <b>Schizophrenia:</b>    | 14,000 people <sup>25</sup>                      |
| <b>IBD:</b>              | an estimated 20,792 people                       |
| <b>Type 1 Diabetes:</b>  | 21,450 people <sup>26 27</sup>                   |
| <b>Bipolar Disorder:</b> | an estimated 30 - 40,000 people <sup>28 29</sup> |

<sup>24</sup> Moore, 2013, p. 85

<sup>25</sup> Ellis & Collings, 1997, p. 11

<sup>26</sup> Wu *et al*, 2005, p. 197

<sup>27</sup> Statistics New Zealand, 2016

<sup>28</sup> Mental Health Commission, 2011, p. 5

<sup>29</sup> Statistics New Zealand, 2016

## Incidence

Incidence refers to the number of people who develop a disease over a specified period of time (usually a year).<sup>30</sup>

In 2016, an estimated 1,796 new IBD cases were diagnosed, representing an incidence rate of 38.1 new patients per 100,000 population. Over the 10 years from 2003 to 2013, it is estimated that the number of new IBD cases each year has increased by 8.1% per year. Independent of the increase in population, the rate at which New Zealanders are developing IBD is increasing.

*Over the 10 years from 2003 to 2013, it is estimated that the number of new IBD cases each year has increased by 8.1% per year. Independent of the increase in population, the rate at which New Zealanders are developing IBD is increasing.*

## Mortality

There is a pattern of significantly increased mortality for Crohn's disease patients, and uncertainty about whether there is an increase in mortality for ulcerative colitis patients. This is established in international studies with consistent findings from New Zealand research.<sup>31</sup> Most deaths related to Crohn's disease occur in older aged individuals and showed they were at risk of digestive diseases, digestive cancers and respiratory diseases.

In previous times, severe IBD was a life-threatening disease associated with high death rates. With modern treatment, IBD death rates have fallen. A recent meta-analysis of CD mortality by [Canavan et al \(2007\)](#) combined the results of 13 studies and reported that the overall 'age-adjusted mortality risk from Crohn's disease is over 50% greater than the general population'<sup>32</sup>.

However, lower mortality has healthcare cost implications, as people live longer and require more treatment.

## Prevalence projections

Indicatively, New Zealand will have approximately doubled its IBD population by 31 December 2026, given current<sup>33</sup> population growth projections and assuming the same rate of prevalence growth estimated to have been experienced over the last 12 years is continued.

**Figure 2** compares the trends in three possible scenarios modelled to illustrate a range of possible future prevalence outcomes. All three scenarios project the compounding increases per annum experienced from 2004 to 2016 forward to 2026. The middle 'historical' scenario models the same rate of increase (no change). The 'slower' and 'faster' scenarios assume the rate of change in prevalence slows (decreases) or gets faster (increases) by 25% respectively. The 25% figure was chosen purely to illustrate a range of possible future outcomes and a different figure can be substituted into the model to illustrate a different range of outcomes as desired.

The concept of compound prevalence has been used internationally and is recognised in New Zealand.<sup>34</sup> It describes the effect of a disease with increasing incidence which is diagnosed at a younger age and which is not universally fatal. This compounding is further compounded by New Zealand's growing population.

<sup>30</sup> Harvard School of Public Health, 2017

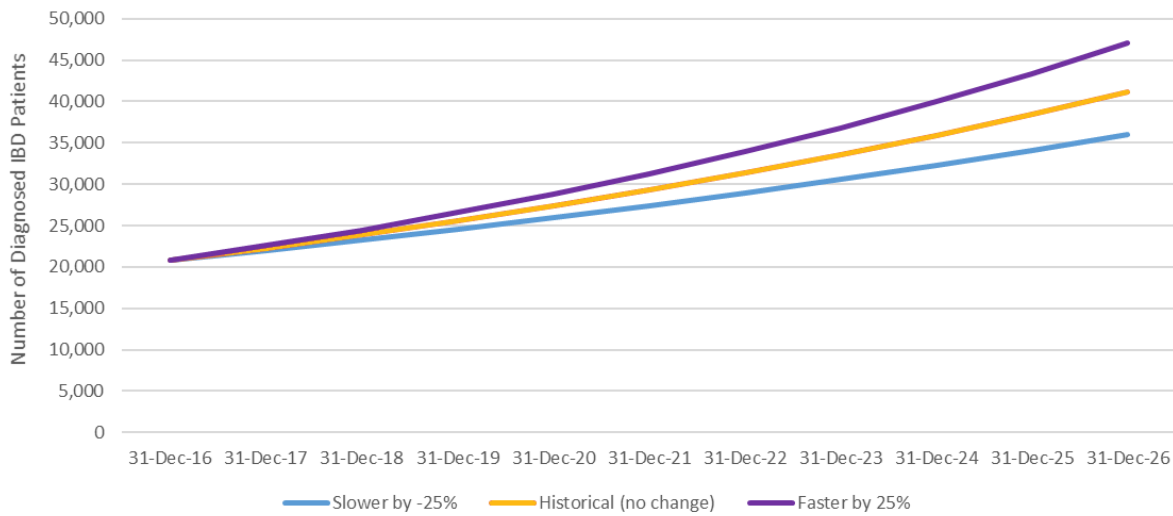
<sup>31</sup> Forbes, 2013, p. iii

<sup>32</sup> Canavan & Abrams, 2007, p. 861

<sup>33</sup> Statistics New Zealand, 2017

<sup>34</sup> Su, Gupta, S, & Gearry, 2016, p. 6

Figure 2: IBD Population Growth Scenarios



Source: Compounded growth rate based on growth rate calculated from regional studies over period 2004 to 2016

### International comparisons

IBD is presented as an emerging global disease<sup>35 36</sup> from developed world data, although less data are available from developing countries. Prevalence is expected to increase further due to the early age of onset, its currently incurable nature and low mortality of IBD patients.<sup>37</sup>

Studies report that Western countries have the highest prevalence, and New Zealand is among the highest of those (Figure 3).

Figure 3: Estimated Prevalence Internationally

| Country     | Rate as % of population | Proportion of people affected | Source                               |
|-------------|-------------------------|-------------------------------|--------------------------------------|
| Canada      | 0.65%                   | 1 in 154                      | CCF Canada                           |
| USA         | 0.50%                   | 1 in 201                      | CCF of America 'The Facts about IBD' |
| New Zealand | 0.44%                   | 1 in 227                      | This Report                          |
| Australia   | 0.33%                   | 1 in 303                      | PWC Report 2013                      |
| Europe      | 0.30%                   | 1 in 333                      | Burden of IBD Europe                 |

Sources: As quoted

While there are ethnic and other differences in the make-up of the populations of these countries, there is a noted increase in IBD the further a population is from the equator. In this context, the estimated New Zealand prevalence seems to 'sit about right'.

<sup>35</sup> Molodecky, et al., 2012, p. 52

<sup>36</sup> Kaplan, 2015, p. 720

<sup>37</sup> Burischa, Jess, Matteo, & Lakatos, 2013, p. 323



### 3. Direct Costs

#### Overview

As the number of people in New Zealand with IBD continues to rise, so too will the cost to the healthcare system, patients and their families.

As noted in previous sections, there is little data available in New Zealand concerning IBD. Accordingly, this study has applied that which is available. An overview of the method and data sources used is in Appendix B.

#### Hospital admissions

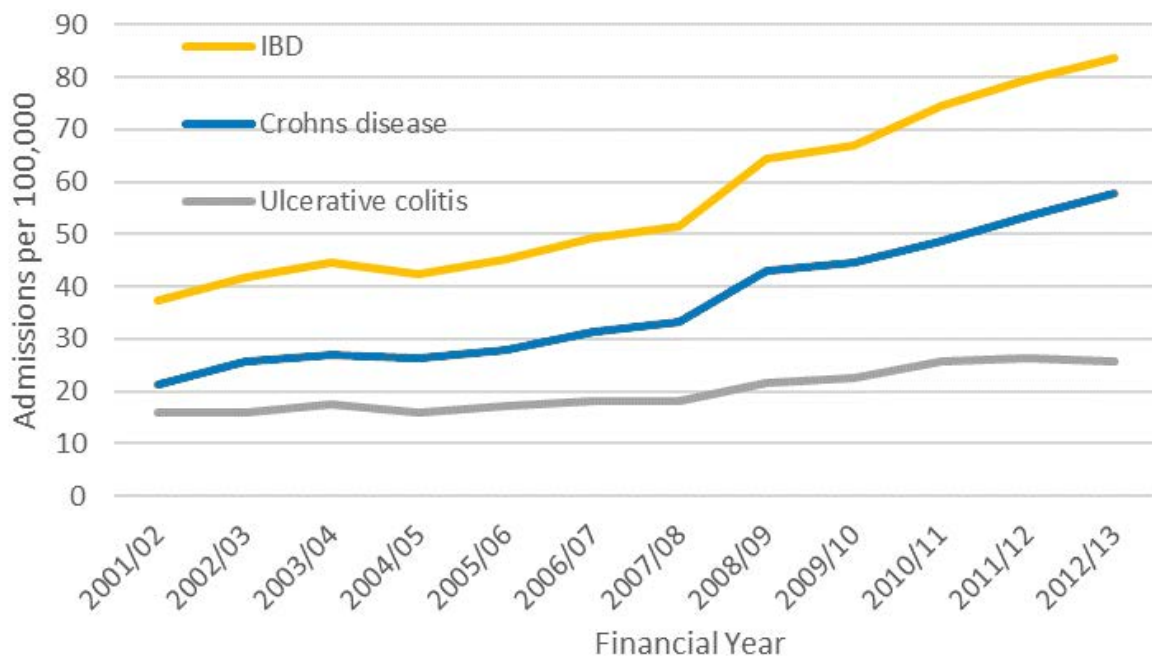
National hospital admissions for IBD were studied by Milne for the period 1 July 2001 to 30 June 2013.<sup>38</sup>

There were 28,369 hospital admissions during the study period.

As shown in **Figure 4**, hospital admission rates for both Crohn’s disease and ulcerative colitis increased over the study period, with the largest increase attributable to Crohn’s disease.

Hospital admission costs increased in parallel with admission rates.

Figure 4: IBD Admission Rates

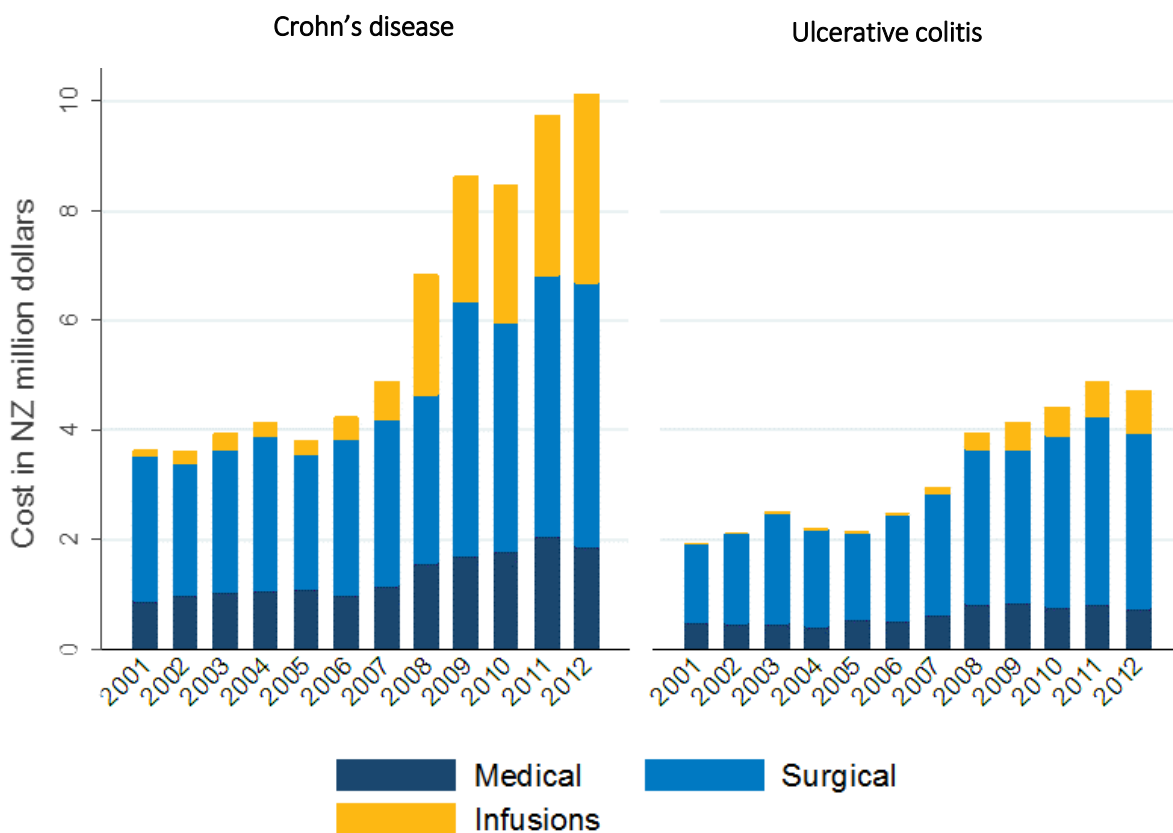


Source: Richard Milne, *Inflammatory Bowel Disease*

The most significant cause of the increase in annual costs for Crohn’s disease was infusions of therapeutic substances, most commonly infliximab or iron, as illustrated in **Figure 5**.

<sup>38</sup> Milne, 2017, p. 3

Figure 5: Annual Cost of Medical and Surgical Hospital Admissions and Therapeutic Infusions\* for Individuals with IBD, July 2001 to June 2013 in 2015/16 NZ Dollars\*\*



Source: Richard Milne, *Inflammatory Bowel Disease*

\*Most therapeutic infusions are day stays.

\*\*Costs are unadjusted for population increases. 2001 = FY2001/02 etc.

The New Zealand Child and Youth Epidemiology Service reports on IBD in New Zealanders aged 0-24 years using information from the National Minimum Dataset.<sup>39</sup>

### Hospital inpatients

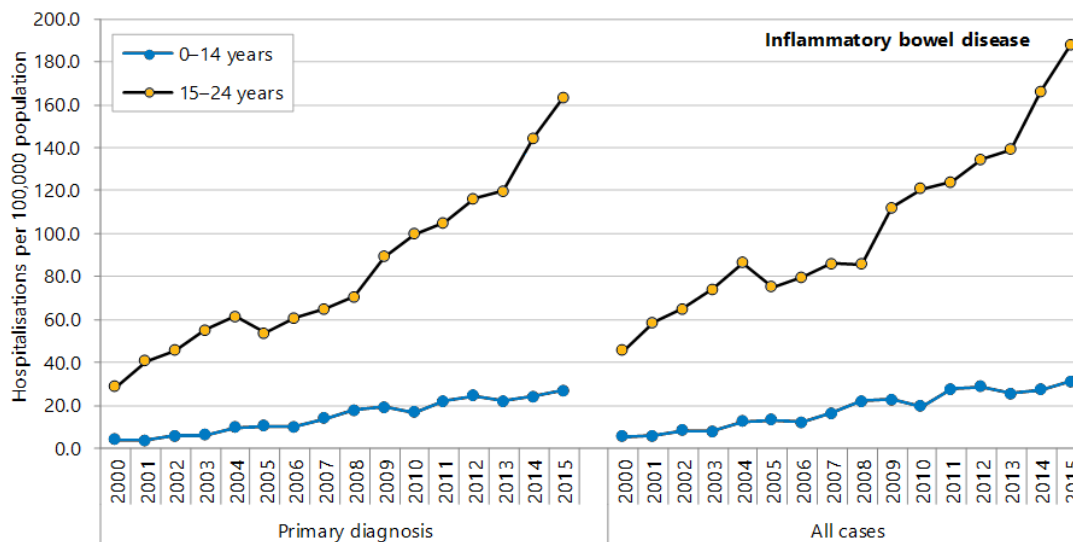
A summary of hospital discharges was obtained from the Ministry of Health for the year 2015/16<sup>40</sup>. The data showed Casemix-funded hospitalisations for IBD (International Classification of Disease-10 codes K50-K51) and was summarised by diagnosis-related group (DRG) with number of discharges, average length of stay and the estimated average cost for each DRG procedure.

Figure 6 shows admissions over time.

<sup>39</sup> Simpson, et al., 2016, p. 442

<sup>40</sup> MoH 2015/16 publicly funded Casemix hospital discharges with a primary diagnosis of K50 or K51.

Figure 6: Hospitalisations for IBD, 0-24 year olds, by age group, NZ 2000-2015



Source: NZ CYES 2016

The total estimated cost was \$16.9 million as shown in **Figure 7**. Of the 30 DRGs reported, the top six accounted for 89% of the estimated total cost. The same six DRG codes also accounted for 84% of the total length of stay involving an overnight stay and 95% of the number of patients discharged.

Figure 7: Top Diagnosis-Related Groups: those which Most Drive Hospitalisation Cost

|  | Est. Total Cost     |               | Discharges (No. of Patients) | Average Length of Stay (Days) | Total Length of Stay (Days) |
|--|---------------------|---------------|------------------------------|-------------------------------|-----------------------------|
| Inflammatory Bowel Disease W/O CC                          | \$9,298,463         | 55.0%         | 4,155                        | 0.3                           | 1,247                       |
| Major Small and Large Bowel Procedures W Catastrophic CC   | \$1,689,284         | 10.0%         | 67                           | 17.8                          | 1,193                       |
| Major Small and Large Bowel Procedures W/O Catastrophic CC | \$1,504,106         | 8.9%          | 112                          | 9                             | 1,008                       |
| Colonoscopy W/O Catastrophic or Severe CC                  | \$1,058,786         | 6.3%          | 215                          | 5.1                           | 1,097                       |
| Inflammatory Bowel Disease W CC                            | \$934,198           | 5.5%          | 215                          | 3.7                           | 796                         |
| Colonoscopy W Catastrophic or Severe CC                    | \$599,939           | 3.5%          | 67                           | 8.3                           | 556                         |
| All other 25 DRG codes combined                            | \$1,823,114         | 10.8%         | 234                          | 6.9                           | 1,167                       |
| <b>TOTAL IBD DISCHARGES K50-K51 CASEMIX FUNDED</b>         | <b>\$16,907,890</b> | <b>100.0%</b> | <b>5,065</b>                 |                               | <b>7,062</b>                |

\*After removing discharges with LOS <1

Source: Ministry of Health summary for estimated IBD Casemix discharges and costs

The average length of stay in hospital (ALOS) for IBD discharges, excluding people who do not spend at least one night in hospital, is approximately 3.4 days for each of 2,090 periods of hospitalisation.

## Non-Casemix

Hospitalisation data provided by the Ministry of Health and quoted in this section was based on Casemix System funding. The Ministry of Health estimates that “Casemix based funding accounts for a significant proportion of all DHB funding, varying between 28% and 29%”.<sup>41</sup> Examples of funding not reported under Casemix include emergency department, outpatient department and GP reimbursements.

This means 71% to 72% of DHB funding is not funded by Casemix and not available to this study within its scope and time. Some of the areas not covered by Casemix System Funding relevant to IBD are discussed in the ‘Other Direct Costs’ section below.

## Potentially avoidable surgery and treatment

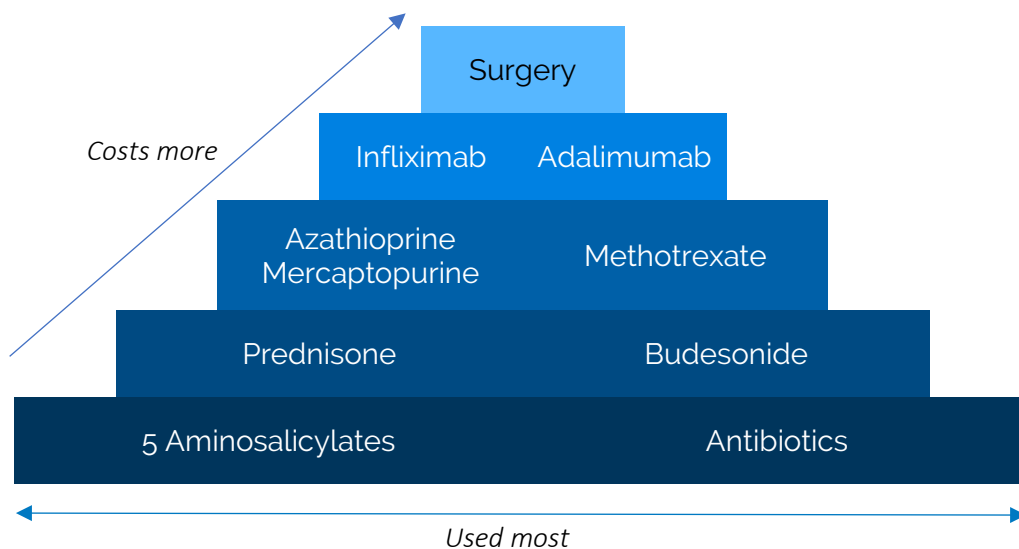
Delayed diagnosis or lengthy pathways to treatment resulting in additional time before the appropriate treatment is initiated can lead to the need for more invasive intervention. For example, surgery may be required, whereas if correct intervention occurred at an earlier stage, drugs would have been sufficient.<sup>42</sup> This leads to increased suffering for the patient and increased costs to the health system.

## Pharmaceuticals

### *Current treatment options and pathways*

The two main goals of pharmacological treatments for IBD are to induce and maintain remission. The current treatment pathway is usually a ‘step-up’ approach, reserving the most expensive medications for those who have failed to respond to those medications at the bottom of the pyramid. This pyramid approach is represented in (Figure 8) below.

Figure 8: Traditional Approach for Treatment of IBD in New Zealand



Source: Adapted from PHARMAC presentation

<sup>41</sup> Ministry of Health, 2017

<sup>42</sup> Gapsin, Van Langenberg, Holtmann, Hetzel & Andrews, 2012, p.e84

The following types of therapy are used in this approach:

1. *5 Aminosalicylates (5-ASA)* are used to suppress low-grade inflammation. They are frequently the first medicines used in treating mild-to-moderate episodes of IBD, but are less effective in severe, acute flare-ups.<sup>43</sup>

Mesalazine, a subgroup of these drugs, is widely used in IBD treatment in New Zealand.

2. *Oral steroids* treat the symptoms of IBD including acute flares. These drugs reduce inflammation, fever and diarrhoea, and relieve abdominal pain. However steroids are not suitable for maintenance or long-term treatment, due to sometimes serious and irreversible side effects.
3. *Immunomodulators* are a class of drugs used to help stop inflammation by suppressing the immune response<sup>44</sup> that would otherwise release inflammation-inducing chemicals in the intestinal lining. They significantly improve the patient's condition and allow a decrease in steroid requirements. These medications can take up to several weeks to months to show an effect.
4. *Biologics or anti-TNF $\alpha$  medications* are a more recent class of therapies that make use of manufactured antibodies to target TNF $\alpha$  (Tumour Necrosis Factor-alpha), a protein involved in the body's immune response which is present in large amounts in people with IBD, resulting in excessive inflammation.<sup>45</sup>

Biologics are highly effective in the majority of patients and have brought about a paradigm shift in the treatment of moderate to severe IBD.

Two anti-TNF $\alpha$  biologic medications are funded for IBD in New Zealand: infliximab is licenced and funded for the treatment of Crohn's Disease and Ulcerative Colitis, and adalimumab is funded for Crohn's Disease. Because of their cost, most patients who receive either adalimumab or infliximab must have failed to respond adequately to those medications at the bottom of the pyramid before they can be funded in New Zealand.

### *Costs and use*

Data and information was obtained from Pharmac regarding the cost and use of pharmaceuticals in the treatment of IBD<sup>46</sup> in New Zealand and this was corroborated by clinical and patient feedback from the IBD working group. Pharmac advised that their data are primarily intended to track what is dispensed for the purposes of reimbursements, rather than what any drug might be used for. As a consequence, the usage and cost of several drugs used for treatment of IBD cannot be quantified for IBD alone.

A summary of the use and cost of Pharmac-funded IBD drugs in 2016 is shown in **Figure 9**.

---

<sup>43</sup> Crohn's & Colitis Foundation, 2017

<sup>44</sup> Crohn's & Colitis UK, 2017

<sup>45</sup> Crohn's & Colitis UK, 2017

<sup>46</sup> PHARMAC, 2017

Figure 9: IBD Pharmaceutical Summary Type and Use for 2016

|   |                    |  |                  |                            |
|---|--------------------|--|------------------|----------------------------|
| <i>New biologics being considered (monoclonal antibodies)</i> | Golimumab          |  |                  |                            |
|   | Ustekinumab        |  |                  |                            |
|   | Vedolizumab        |  |                  |                            |
| <i>Biologics (anti-TNF<math>\alpha</math> medication)</i>     | Adalimumab         | Total cost: \$19,097,419   | Patients: 1,114  | Cost per patient: \$17,143 |
|   | Infliximab         | <i>Used for multiple conditions: IBD patients cannot be separated out.</i> |                  |                            |
| <i>Immunomodulators</i>                                       | Azathioprine       | <i>Used for multiple conditions: IBD patients cannot be separated out.</i> |                  |                            |
|   | Mercaptopurine     |  |                  |                            |
|   | Methotrexate       |  |                  |                            |
| <i>Immunosuppressants</i>                                     | Cyclosporin        | <i>Used for multiple conditions: IBD patients cannot be separated out.</i> |                  |                            |
| <i>Anti-inflammatories</i>                                    | Steroids (various) | <i>Used for multiple conditions: IBD patients cannot be separated out.</i> |                  |                            |
| <i>5 Aminosalicylates (5-ASA)</i>                             | Mesalazine         | Total cost: \$8,935,760  | Patients: 12,264 | Cost per patient: \$729    |
|   | Olsalazine         | Total cost: \$150,362  | Patients: 317    | Cost per patient: \$479    |
|   | Sulphasalazine     | Total cost: \$874,339  | Patients: 6,799  | Cost per patient: \$129    |
| <i>Antibiotics</i>  |                    | <i>Used for multiple conditions: IBD patients cannot be separated out.</i> |                  |                            |

*Total Identifiable Costs: \$29,057,880*

Source: Adapted from PHARMAC presentation

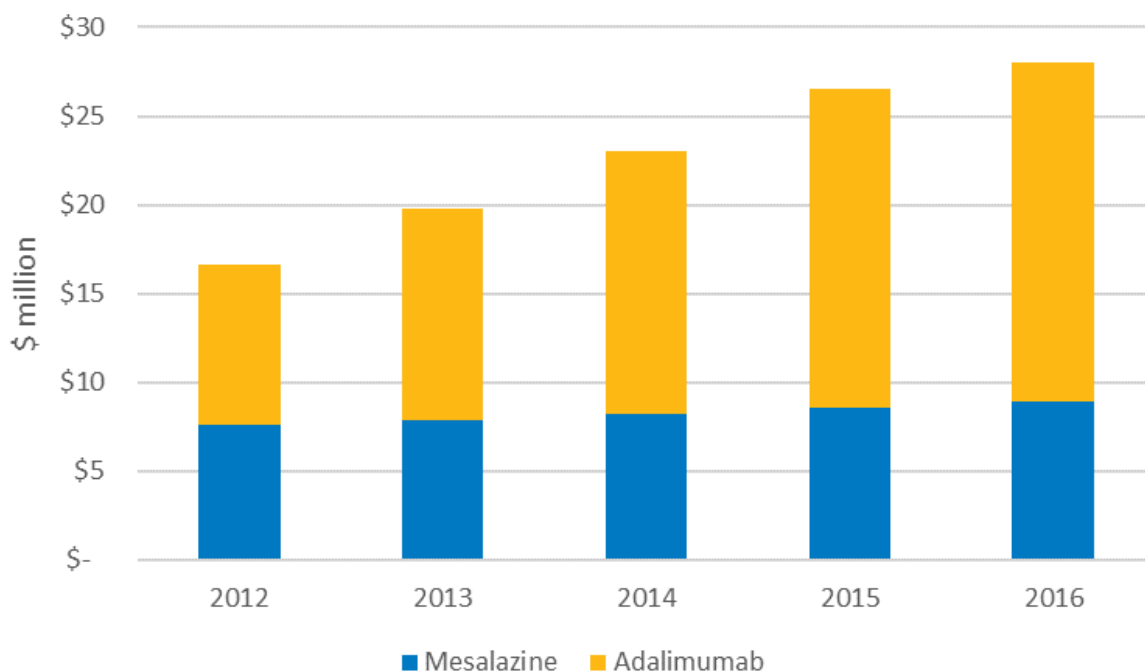
#### *Cost and use of mesalazine and adalimumab*

Mesalazine and adalimumab together account for 96% of the identifiable IBD drugs cost, with adalimumab representing the majority of that cost. Both are increasing in terms of the number of patients using them and total cost. **Figure 10** shows that the cost per patient per year for both drugs remained relatively stable. Total costs rose in line with growth in patients.

Over the period of 5 years from 2012 to 2016, the use of mesalazine increased by an average 2% per year. This translates to a growth in total cost of \$1.2 million, or 17%, in that period.

Over the period of 5 years from 2012 to 2016, the use of adalimumab increased by an average 21% per year from 523 patients to 1,114. This translates to a growth of total cost of \$10.1 million, or 113%, in that period. (See **Figure 10** page 27.)

Figure 10: Cost of Mesalazine and Adalimumab



Source: PHARMAC data

*Issues of concern in use of pharmaceutical treatments*

Feedback from both patients and clinicians indicates that there is significant variability in treatment patterns and pathways for IBD patients in New Zealand. It was noted that while medications that are often used early in the course of the disease are less expensive, they may be less efficacious for those with moderate to severe disease. If these less efficacious medications are used for long periods of time while uncontrolled inflammation continues, complications could occur, associated with a less favourable long-term prognosis.

The CCNZ IBD Workshop Members agree that:

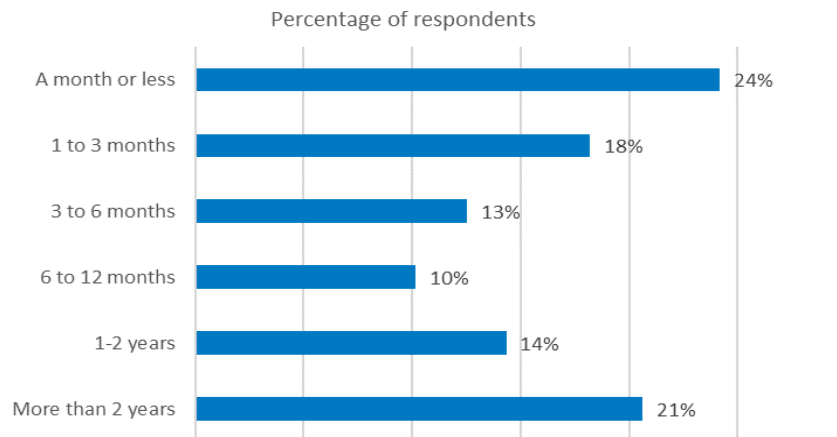
1. *Patients are suffering as a result of inability to meet requirements.*  
The strict criteria limiting the use of biologic medications mean that many patients who could benefit from receiving them early in the course of their disease, may not meet the requirements. If and when funding is finally approved for these medications, patients may have had to trial several other less efficacious medications over the course of several months.
2. *Patients who do not respond, or who lose response to the anti-TNF $\alpha$  medication over time, have no other funded options.*  
In countries with populations to which New Zealand is often compared, including Australia, patients have other pharmaceutical options including new biologic medications with different modes of action. For New Zealand patients there are currently no other funded alternatives beyond the TNF- $\alpha$  inhibitor class.
3. *There are inequities in prescribing patterns between DHBs.*  
There is an apparent strong correlation between access to pharmaceutical therapies and the number of gastroenterologists in the region. Patients in areas without gastroenterology specialists tend to have less access to pharmaceutical therapies.

## General Practices

Most people present to their General Practitioner (GP) when they first get IBD symptoms.

There is no available data around the number of patients who are treated for IBD by their GP, whether this is pre or post IBD diagnosis, or the cost of these services. Anecdotally, evidence from the patient community is that visits to the GP are frequent.

Figure 11: Time from First Presentation to Diagnosis



Source: CCNZ Survey 2017 (n=331)

The CCNZ IBD Workshop Members provided examples and references that show IBD is poorly understood among GPs.<sup>47</sup> This is one reason that IBD often takes some time to diagnose. Both factors contribute to a widely reported feeling in the patient community that suffering is greater than it needs to be.<sup>48</sup> Delayed diagnosis and increased testing also increases direct costs to the health system and patients.

Responses to the 2017 CCNZ survey of New Zealanders with IBD (**Figure 11**)<sup>49</sup> showed that while 24% of respondents recall being diagnosed in a month or less, for 35% of respondents it was more than a year from first presenting to a medical professional to obtaining their initial IBD diagnosis.

About one in five reported that a diagnosis took more than two years.

While this figure may be influenced by the fact that 30% of survey respondents had been diagnosed more than 16 years ago, in the same survey, 53% of respondents strongly disagreed or disagreed with the statement “The amount of time it took to be diagnosed with IBD felt adequate”. Only 31% of respondents strongly agreed or agreed.

A study by the Royal Adelaide Hospital<sup>50</sup> reported that GPs are often the first point of contact for initial presentation of symptoms as well as disease flares. This is problematic as the study also showed that:

- 37 per cent of the 409 GPs surveyed responded they were ‘uncomfortable’ with IBD management
- 71 per cent and 91 per cent were uncomfortable with the use of immunomodulators and biologics respectively
- GPs’ comfort with managing IBD did not correlate with their IBD specific knowledge

<sup>47</sup> Tan, Holloway, Lange, & Andrews, 2012, p. 801.

<sup>48</sup> CCNZ IBD Burden of Disease Study workshops March and April 2017

<sup>49</sup> CCNZ Survey, 2017

<sup>50</sup> Pricewaterhouse Coopers, 2013, p. 9



## Patient and Caregiver Direct Costs

IBD causes direct costs for patients and caregivers. Costs incurred vary and include (but are not limited to):

- GP visits
- transport to visits (a considerable cost to patients who live rurally and may also have to factor in accommodation)
- prescriptions
- additional personal items (for example colostomy bags, nutritional supplements and special dietary requirements), and
- other out of pocket expenses.

Some transport costs (i.e. for those who live rurally) will be reimbursed and so the burden shifts from patients and caregivers to wider society via healthcare costs.

It is estimated<sup>51</sup> that people with IBD and their caregivers spend on average between \$1,602 and \$1,945 each per year on costs directly related to IBD. Across the New Zealand IBD population, this is an estimated total cost of between \$33.3 million and \$40.4 million per year.

## Other Direct Costs

- *Emergency department*  
Many IBD cases present to hospital emergency departments due to the nature of the symptoms. There is no currently available data around the number of patients who present with IBD symptoms, nor the cost of the services they receive.
- *Outpatients*  
Many IBD cases are managed by hospital outpatient services. While there are busy IBD clinics in some New Zealand hospitals, there is no currently available data around the number of IBD patients who are being managed, nor the cost of the services they receive.
- *Mental health*  
IBD is a challenging disease with a significant psychological aspect. The degree to which mental health services are accessed, and the cost of these services, is not known.
- *Private medical care*  
Not all patients with IBD use the publicly-funded health system. With major health insurers covering GPs, specialists and surgical procedures depending upon policies held, those people diagnosed with IBD often exercise a choice to access private healthcare. There is no currently available data around cost of private medical care for IBD. Anecdotally, there is evidence to suggest that there is inequity between DHBs in terms of treatment timeliness depending on whether a patient is with a private or public provider. For example, in one DHB a private patient may access treatment more quickly than a public patient, while in another DHB the opposite may be true.

---

<sup>51</sup> CCNZ Survey, 2017



## 4. Indirect Costs

---

### Overview

In addition to the more obvious direct costs of IBD in New Zealand, there are also several less immediately obvious indirect costs. Being less obvious, though, does not mean they are not real. Hence, this section describes and estimates them.

IBD is a chronic condition, therefore these costs are ongoing to some degree for the remainder of the patient's life.

Similar to other estimated costs related to IBD, little data exists in New Zealand concerning IBD. Accordingly, this study has applied what is available. An overview of the method and data sources used for estimating indirect costs is in Appendix C.

This section draws on data from a member survey conducted in March 2017 by CCNZ at the request of this study. While the survey is useful in helping determine the burden of the disease, such surveys often contain response bias and other biases.

Across the many sources of disparate data from New Zealand and references from other countries, there is evidently a wide variance in the patient experience. While some patients report that their symptoms or the effects on their life are largely managed or under control, there is a not insignificant number for whom the negative effects are extreme.

*“Our marriage is actually stronger now than ever; I heard that a sick child can be enough to break up previously happy marriages but I think we have become closer instinctively, knowing that a strong team can put up a better fight and face the bad things life throws our way. We have made the decision that I will not go back to work, which is a blow financially, but it will ensure a more secure life for our children and a better chance for my husband to advance in his career.”*

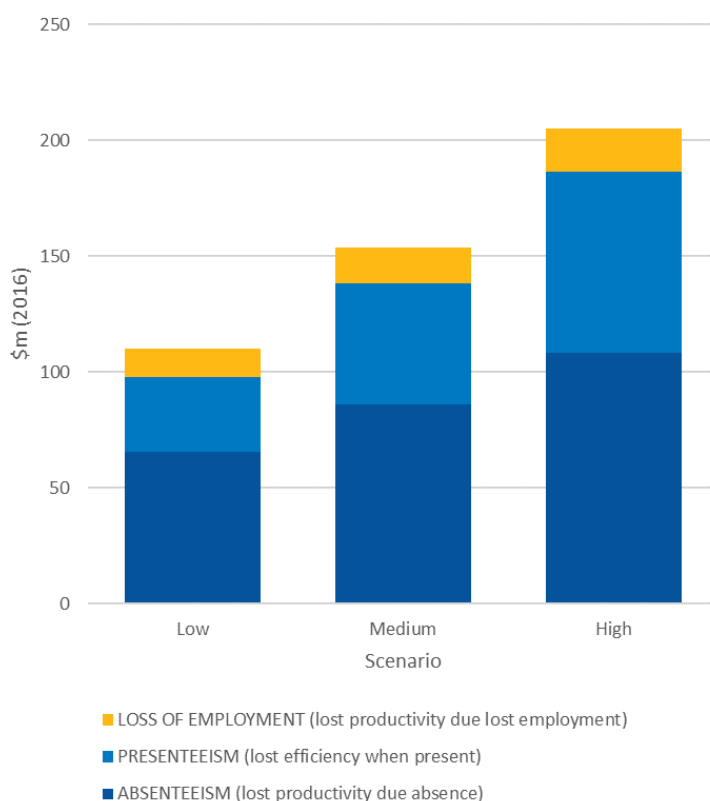
– parent of a young child with Crohn's disease

### Employment-related costs to national productivity

It is estimated that employment-related IBD indirect costs reduce New Zealand's GDP by approximately \$160 million (2016). Modelling scenarios where the key drivers of this figure are altered by a percentage to illustrate low and high possibilities, it is estimated that the low scenario is \$115 million and the high \$212 million.

Key components of this overall figure are shown in **Figure 12**.

Figure 12: Estimated Employment-Related Indirect Cost of IBD Per Annum to NZ GDP



Source: Survey and statistical data outlined in Appendix C

### Absenteeism

Lost productivity due to absence from the workplace because of IBD is estimated at approximately \$86 million per year. This figure is made up of two components: loss of productivity and management costs incurred by the absence. Loss of productivity due to absences caused by IBD is derived from an estimated average of 9 days<sup>52</sup> off work each year due to IBD for each person in the IBD population.

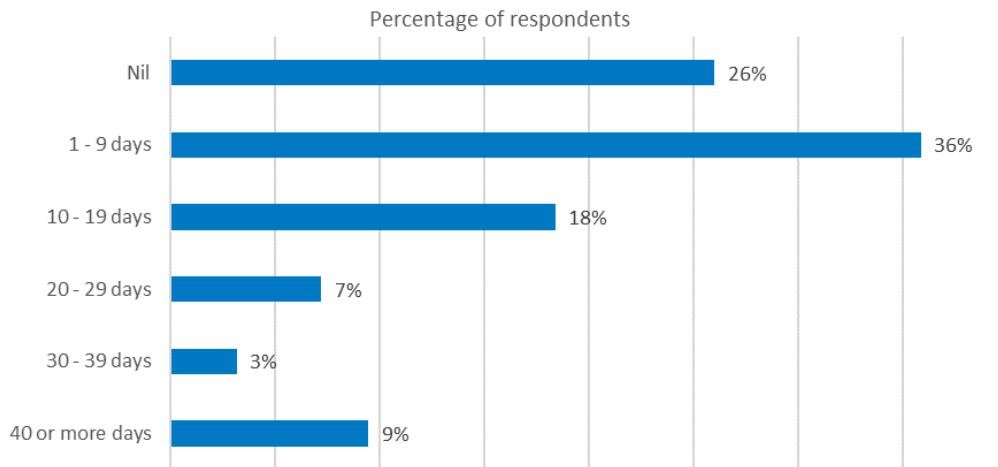
The CCNZ member survey also showed, as compiled and illustrated in **Figure 13**, that half of the 219 respondents attributed absence from work for 6 or more days a year either to their own IBD or having to care for dependents with IBD. One in five attributed absences from work of 20 or more days per year to IBD. Absences are typically due to hospitalisation, surgery, fatigue and recovery, pain, other symptoms of the disease, or caring for dependents.

*“In remission my energy levels are not the same as prior to diagnosis, so I am less productive and have reduced my work hours so that I have the energy left for family and relationships, and better work life balance.”*

– IBD patient

<sup>52</sup> CCNZ Survey, 2017

Figure 13: Days off work per year due to IBD



Source: CCNZ Survey 2017 (n=219)

In Australia in 2013, PwC's analysis found that 43% of people with IBD in paid employment have an average of 7.2 lost days of work per annum.<sup>53</sup>

Additional work for management to make other arrangements because of absenteeism is estimated at 30 minutes per day of absence.<sup>54</sup>

### Presenteeism

Lost productivity owing to impaired performance while at work because of IBD is estimated at approximately \$52 million per year. The 2017 CCNZ survey found 57% of 223 respondents reported that either their own IBD or IBD of their dependents influenced their work productivity on more than 10% of their working days. Slightly more than one in four respondents reported reduced productivity of over 25% on days affected. IBD patients' performance at work can be affected by stress, fatigue and feeling generally unwell, among other things.

In Australia, four randomised clinical trials incorporating presenteeism reported a mean reduction of work productivity due to IBD ranging from 34% to 48% per cent.<sup>55</sup>

### Loss of employment

Lost productivity due to people downgrading their employment status (and therefore their working hours) due to IBD is estimated at around \$16 million per year.

Some IBD patients' career trajectories are forced to change after too many absences, meaning their career of choice is incompatible with the fluctuating state of their health. Some patients choose to reduce their working hours (which may necessitate a change in career / occupation) as stress is a risk factor in triggering a disease flare.<sup>56</sup>

<sup>53</sup> Pricewaterhouse Coopers, 2013, p. 35

<sup>54</sup> BusinessNZ, 2015

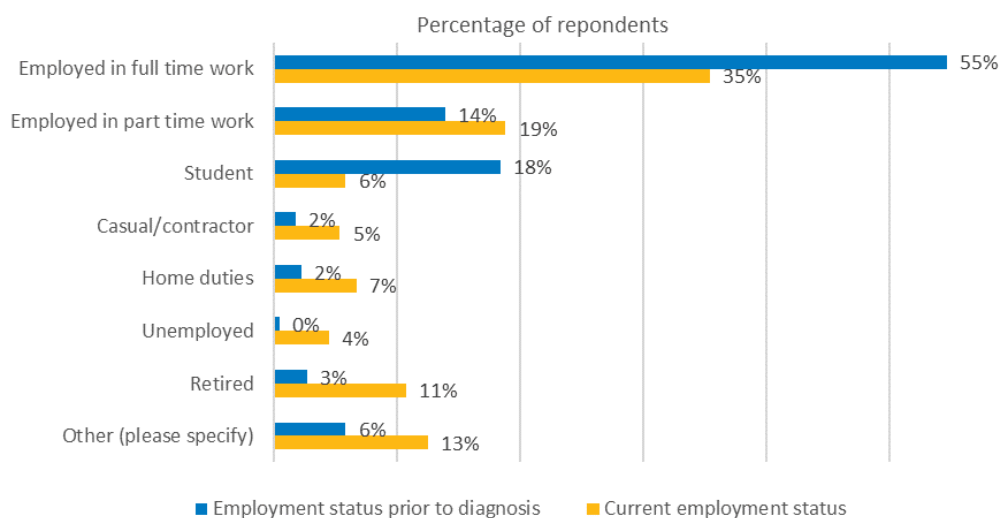
<sup>55</sup> Pricewaterhouse Coopers, 2013, p. 7

<sup>56</sup> Crohn's & Colitis Foundation of America, 2009

European studies have been summarised to conclude that the long-term disability rate, economic and social impact of IBD is enormous.<sup>57</sup> Up to 20% of IBD patients in Europe will end up on a disability pension and a further 10% to 25% face unemployment or part-time employment problems. Sick leave is affecting up to half of patients.

As shown in **Figure 14**, the 2017 CCNZ survey reported 55% of full-time respondents were in full time work before being diagnosed with IBD, whereas 35% were currently in full time work. The percentage of people in part-time, casual, or contracting work increased from 16% to 24%. Of the survey respondents who had experienced a change in employment status, 42% reported that their IBD was a major or moderate reason for the change.

Figure 14: Employment Status Change



Source: CCNZ Survey 2017 (n=219)

## Other Indirect Costs

### Welfare costs

While most people with IBD can continue to work, albeit sometimes in a reduced capacity, in the CCNZ 2017 survey of 219 respondents, 5 people, or just over two percent, said they were receiving the Government’s Jobseeker Support payment because of their IBD or having to care for a person with IBD.

This is estimated to cost around \$8 million per year if extrapolated across the IBD population.

### Future lost productivity

As well as impacting work, IBD also impacts schooling, learning abilities, courses and similar activities, which would be expected to achieve a return on investment over time through increased productivity.

In CCNZ’s 2017 survey<sup>58</sup>, respondents who were carers for school age dependents reported that the children were missing on average 20 or more days of school per year in addition to other missed activities such as sports, trips and after school activities.

77% of carers said that their dependents’ IBD condition has had more than a minimal effect on their education. Of these 26% reported thinking that IBD had a major effect on their child’s education, with ‘major’ being the highest rating available in a question with 6 options.

<sup>57</sup> Burisch, Jess, Matteo, & Lakatos, 2013, p. 330

<sup>58</sup> CCNZ Survey, 2017

In the same survey, 77% of respondents thought that their or their dependents' IBD would have more than a minimal effect on future earning potential.

The potential negative effects on future GDP have not yet been estimated. Future lost productivity is especially pertinent, given the relatively early average age of onset of this life-long chronic condition

#### *Lost tax revenue*

Potential tax revenue is lost by patients either voluntarily cutting down their working hours or being forced to take time off work, due to hospitalisation, for example.

#### *Premature death*

Crohn's disease is a risk factor for premature death. There are costs associated with this.

#### *Other support costs*

Other support includes respite and palliative care, counselling and advice, aids and equipment which can be provided either by the public health system, privately, by NGOs and/or by whānau and family. Note that direct costs incurred by patients and caregivers are estimated in the Direct Costs section.

#### *Side effects from pharmaceuticals*

Pharmaceuticals can have a negative effect on the immune system, thereby potentially incurring extra costs associated with treating colds and, in some cases, potentially life-threatening infections. Extra days off work may also result.

## Conclusion

There are major indirect costs associated with IBD. Consideration of these provides further reasons for taking action to improve the pathways of care, including earlier diagnosis, for those with IBD.

From the evidence available to date, even without further research, it is clear that the costs of improving care will be significantly offset through the reduction in indirect costs.

*"Fatigue and pain are big issues for IBD patients as is the anxiety around needing to know where the nearest bathroom is when on outings. Others feel socially isolated as they are not able to do the things they want to do; they feel anxious and have lost confidence in themselves and feel guilty because of the impact their illness has on their friends and families"*

– CCNZ 2017 Survey





## 5. Quality of Life

---

### Overview

In addition to considering the physical and financial burden IBD places on individuals and the New Zealand healthcare system, we have endeavoured in this study to identify the psychosocial costs of IBD borne by patients and their families. These are extensive and, as with many other aspects of IBD management in New Zealand, access to support in dealing with these issues is patchy and inequitable.

Maria Berrett<sup>59</sup>, a Senior Clinical Psychologist at Massey University's School of Psychology and CCNZ IBD Workshop Member, who has been coordinating Health and Cancer Psychology Services for MidCentral DHB patients over the past nine years, has encountered and identified many of the psychosocial issues faced by IBD patients. In an application to undertake PhD research in the area of psychosocial aspects of IBD, Ms Berrett listed some of the psychosocial issues that can result from IBD itself and/or from the treatments including medication and surgery. She noted that these include:

- stress
- sleep difficulties
- social isolation
- pain
- body image concerns
- shame and stigma
- depression, and anxiety, including a wide range of fears and worries, e.g. of:
  - incontinence
  - flares
  - treatment effects including medication side effects
  - diagnostic procedures
  - the impact of surgery and colostomy
  - the unpredictability of the illness
  - reactions of others, and
  - fear of cancer
- impact on relationships, sexual functioning and role changes, and
- issues with adjustment and coping and adherence.

Evidence provided below from the CCNZ 2017 survey of members sheds further light on the extent of these issues and the personal, social and emotional distress suffered by IBD patients and their caregivers and wider families.

### Living with IBD: data from the 2017 CCNZ Survey

The following text, data and graphs were extracted from a report<sup>60</sup> based on the CCNZ 2017 Survey.

#### *Patients' quality of life*

For almost half of patients/caregivers, IBD has had a major impact on their overall future (Figure 15). For 46%, IBD has had a major impact on their intimate relationships, earning potential and ability to participate in recreational activities such as sports. Fortunately, around half believe IBD has a minimal impact on their ability to have a family, maintain friendships and attend family events.

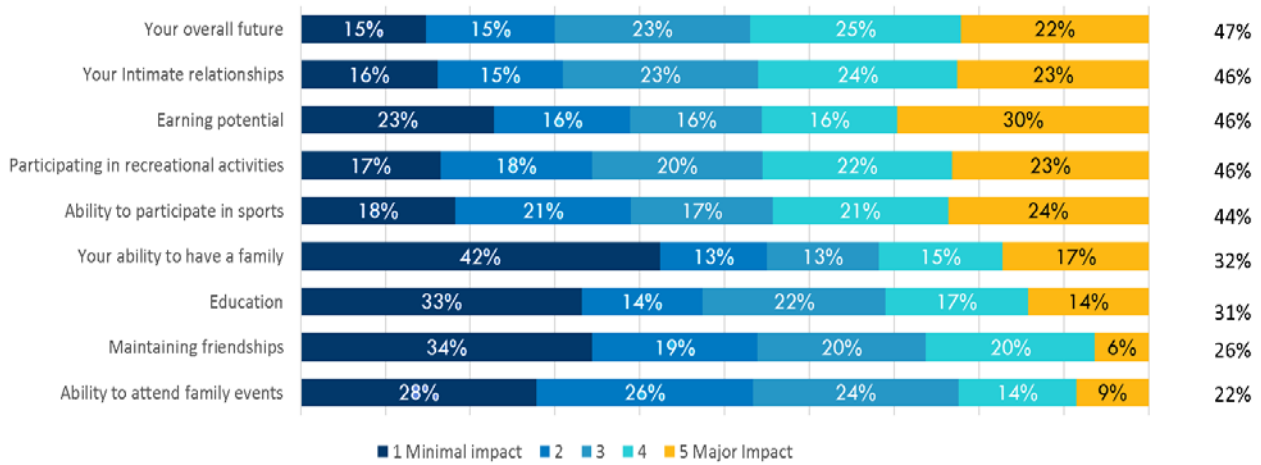
---

<sup>59</sup> Maria Berrett, <http://www.massey.ac.nz/massey/expertise/profile.cfm?stref=273150>

<sup>60</sup> Shannon, 2017

Figure 15: Impact IBD diagnosis has had on a patient's quality of life

Major impact  
% Rated 4 or 5



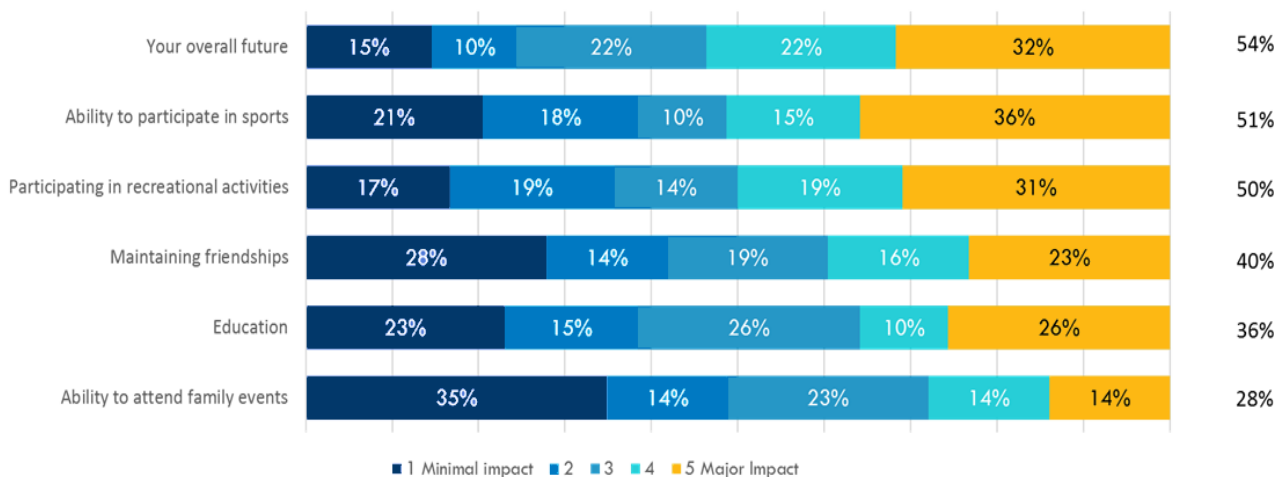
Source: CCNZ 2017 Survey (Sample sizes range from n=151~223, responses are re-calculated to exclude "Not applicable")

### Child's quality of life

Around half of parents feel their child's IBD has had a major impact on their overall future and their ability to participate in sports and other recreational activities (Figure 16). Of those responding to the survey, 1 in 3 parents feel their child's IBD has a major impact on their education.

Interestingly, 2 in 5 parents feel their child's IBD has had a major impact on their child's ability to maintain friendships while another 2 in 5 say it has a minimal impact.

Figure 16: Impact IBD diagnosis has had on a child's quality of life



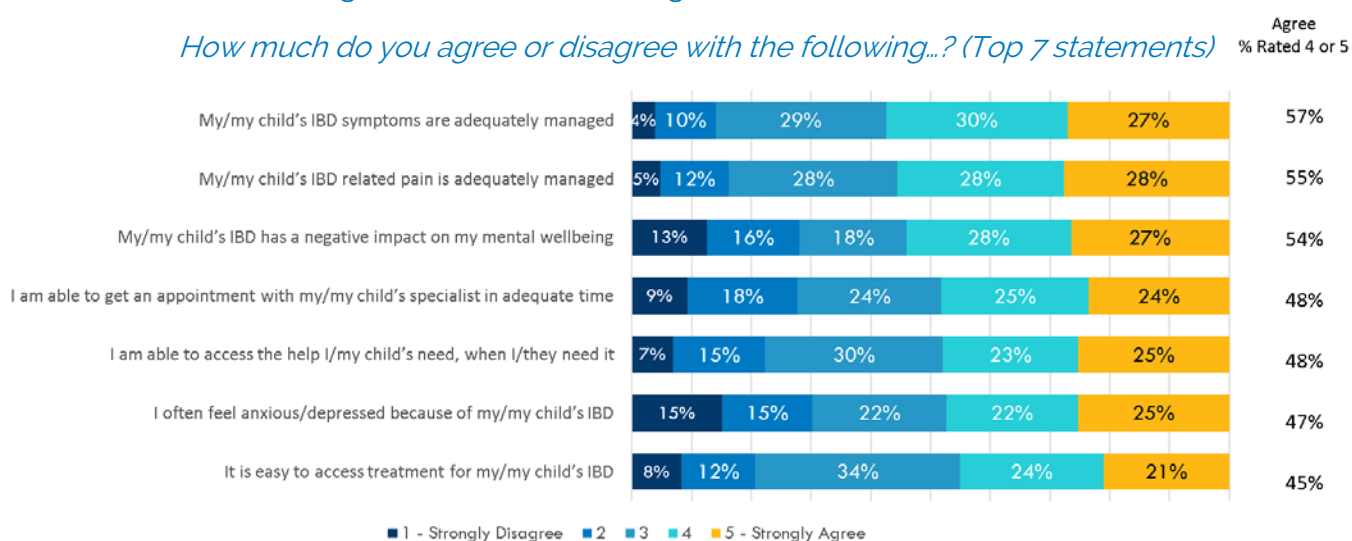
Source: CCNZ 2017 Survey (Sample sizes range from n=39~43, responses are re-calculated to exclude "Not applicable")

*Disease management/access to care*

Over half of parents of IBD patients surveyed agree their child’s IBD symptoms and pain are adequately managed. Parents with IBD feel their own IBD has had a negative impact on their and/or their child’s mental wellbeing with 47% saying they often feel anxious/depressed because of their IBD (Figure 17).

While close to half feel they are able to get an appointment with their specialist in adequate time, 28% disagree and a further 22% feel they are not able to access the help they need when they need it. 21% do not feel they are able to easily access treatment for their IBD.

Figure 17: Disease Management and Access to Care



Source: CCNZ 2017 Survey (Sample sizes range from n=148~207, responses are re-calculated to exclude “Not applicable”)

*Satisfaction with the New Zealand health care system/overall effects*

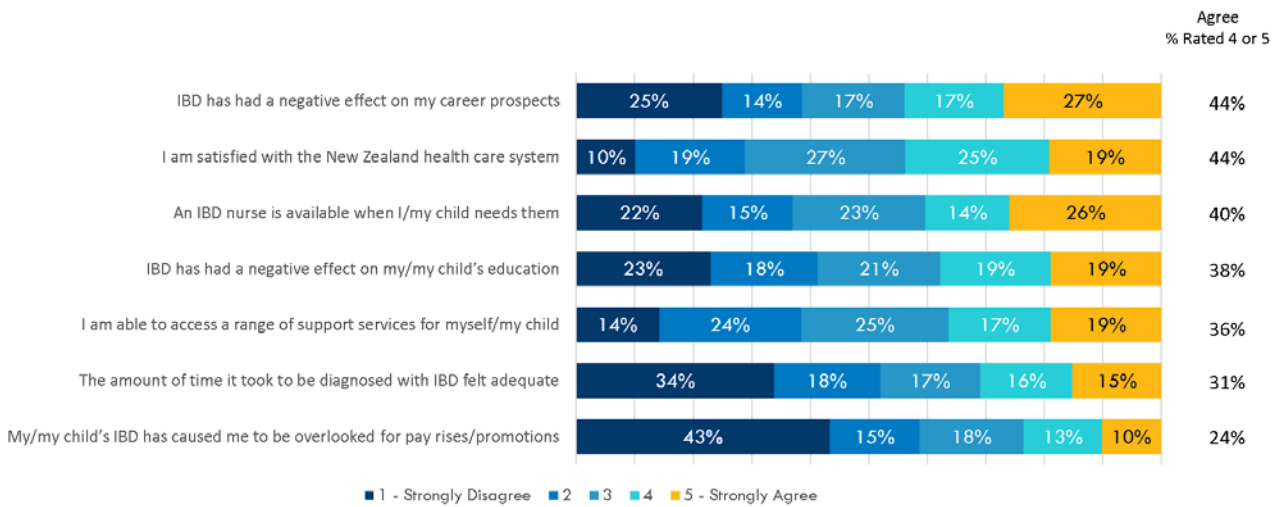
Overall, 44% are satisfied with the New Zealand health care system; however, almost a third are dissatisfied and another 27% are neutral (Figure 18). Patients/caregivers are split on whether they agree or disagree that they are able to access an IBD nurse when they need them, indicating there are differences in the availability of care and support services around the country.

*“I can’t rate my IBD nurse highly enough. She responds quickly to phone calls and emails and always makes sure that I know that I can contact her if my symptoms flare up. She goes over and above to help me as much as possible and genuinely cares about my wellbeing and making sure that I’m getting the services that I need at the hospital. Lots of other IBD patients I know talk about how great she is too.”*

– CCNZ 2017 Survey

Figure 18: Satisfaction with the NZ Health Care System / Overall Effects

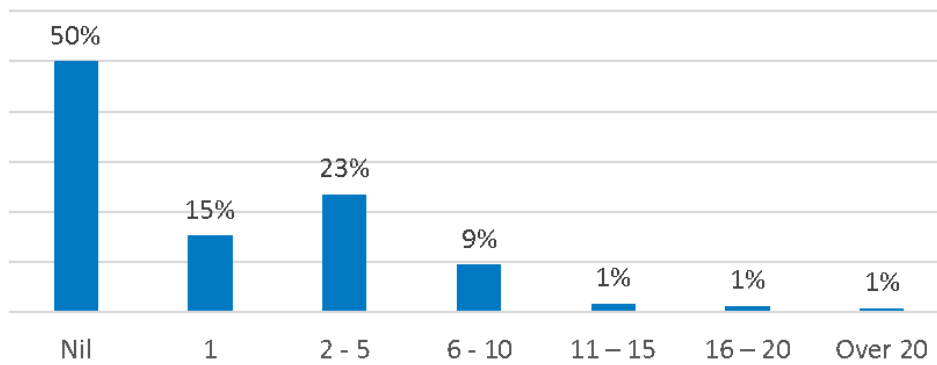
*How much do you agree or disagree with the following...? (remaining statements)*



Source: CCNZ 2017 Survey (Sample sizes range from n=148-207, responses are re-calculated to exclude "Not

While 1 in 3 felt the time it took to be diagnosed with IBD was adequate, half of patients/caregivers disagree with this statement. It should be noted, however, that this is influenced by the length of time with IBD and the diagnostic abilities in the past.

Figure 19: Number of IBD-Related Surgeries per Person (Based on 207 respondents)



Source: CCNZ 2017 Survey (n=207)

*“Access to IBD nurses, specialists, support groups and a public health care system that has minimal user-pay is what is perceived to work well in NZ. Suggestions on how it could work better include better IBD education/understanding of frontline staff, more awareness of IBD in itself, along with research and funding available for medications & nurse specialists. What is needed is earlier and more accurate diagnosis and access to other support such as mental health and nutritional services – essentially a more holistic approach.”*

– CCNZ 2017 Survey

## *Case Study 2: Parent of a Young Child with Crohn's Disease*

**August 2015** – At 18 months of age, very suddenly, overnight, there was a change from normal stools to liquid diarrhoea. We had been using cloth nappies but had to swap immediately for plastic to contain it. Within a fortnight there were streaks of blood. By this time, I had been to our GP and was advised that it's totally normal for toddlers to develop diarrhoea and that we shouldn't worry about it.

**October 2015** – We went to see another doctor as the diarrhoea hadn't stopped. Again, we were told that this is completely normal.

**December 2015** – We went to see a different doctor again as the bleeding had increased, our daughter wasn't gaining any weight and was noticeably shorter than her peers. She also appeared anaemic - losing her rosy cheeks and going completely white. The doctor performed a digital examination and told us she was fine and had we heard of toddler diarrhoea?

**January 2016** – We phoned our GP's office in tears as blood loss was so extreme it looked like our daughter was having periods in her nappies. The practise nurse listened to how we had seen three doctors and told us not to come in as we would probably be given the same advice again, but rather go straight to A and E as they wouldn't send her home until they had figured out what was wrong.

We then had three days in and out of hospital for blood and stool tests, clinical examinations etc. We were told it looked like colitis but that this was unlikely due to her age. The doctor suggested Meckel's diverticulum and ordered a nuclear scan at the hospital. The scan came back negative and more bloods were done. The doctors were confused as to results; the blood work showed no inflammation but the stool sample showed severe inflammation so an endoscopy and colonoscopy were ordered. This was mid-February 2016. My husband stayed in hospital overnight during the flush out as we had a new born baby at this stage.

On February 24th, we received the diagnosis of ulcerative colitis and the next day it was revised to Crohn's disease. We were called in for an appointment to discuss the diagnosis and had it explained to us that younger sufferers of the disease were often resistant to normal treatments, that it would be a long path ahead but that there was every chance our daughter could lead a normal life. She was put on exclusive enteral nutrition for the next 12 weeks.

For these three months, our family avoided eating any solid food around her, to normalise the liquid diet. Our son who was 11 at the time found this rather upsetting - breakfast was eaten in bedrooms, dinner was taken in shifts while our daughter had her bath. Almost immediately improvements were seen, the blood loss eased and then stopped, stools became more mud than water, and she began to gain weight.

Unfortunately, after a trip to my in-laws' she flared up again and the EEN couldn't get things back on track. We were prescribed steroids, soon followed by Pentasa, and then a fortnight later we started on azathioprine.

The steroids worked immediately and we had our rosy little girl back. Unfortunately, 2 months after coming off them she flared again. This was an upsetting time as I had gone to the doctor and advised that I felt a flare was eminent. I was told I was wrong and that our daughter looked great. A week later we were in hospital. Then back on steroids. After nearly 4 months on

We have just this week tested in preparation for methotrexate should she need to switch treatments.

There are no medication costs for our family, and because of her age no GP costs either. Just transport and parking when needing regular bloods (3 in the last 4 weeks) and appointments. The biggest cost is disposable nappies when she has a flare but the child disability allowance covers this expense.

Our daughter remains unaffected by the disease; we believe this is partially due to her young age and partially due to her personality. I myself suffered severe depression post diagnosis and am still under the care of a counsellor. Our youngest child is too little to seem affected. Our eldest who is now 12 is often very angry about it, however. This is understandable as he went from being an only child to having a sick sister and a baby brother in a short space of time. We keep him busy with sport, scouts, trips to see grandparents, but I believe he feels that his life is far worse than it was pre-diagnosis.

Our marriage is actually stronger now than ever; I heard that a sick child can be enough to break up previously happy marriages but I think we have become closer instinctively, knowing that a strong team can put up a better fight and face the bad things life throws our way. We have made the decision that I will not go back to work, which is a blow financially, but it will ensure a more secure life for our children and a better chance for my husband to advance in his career.

## 6. Conclusions

---

### Overview

There is a clear imperative for addressing the standard of care received by IBD patients across New Zealand.

While IBD is a largely hidden disease, as at 31 December 2016, an estimated 20,792<sup>61</sup> New Zealanders (or 1 in 227) have been diagnosed with it. Incidence and prevalence are rising, and as increasing numbers of New Zealanders are afflicted with IBD there is also an awareness among a substantial proportion of those people that the healthcare system could be doing a better job. Many patients struggle to manage their illness while maintaining a sense of self, separate to the disease, and autonomy over their lives.

The total of direct and indirect costs associated with IBD per year in New Zealand is conservatively estimated to be \$245 million. As IBD is a chronic condition, it is projected that costs will escalate in years to come. This includes direct costs, indirect costs and costs from a reduction in the quality of life for IBD patients, their families and communities.

Although New Zealand has one of the highest rates of IBD in the world, the extent of the condition appears to be poorly understood by national level and DHB strategists and planners. As a result, while there are locations implementing best practice, our national standard of care is being eclipsed by many other countries. Australia, for example, has recently carried out a nationwide audit of their IBD care and have just released *Australian IBD Standards: Standards of healthcare for people with inflammatory bowel disease in Australia*. While New Zealand has standards of care for children with IBD (*Management of Inflammatory Bowel Disease in Children and Adolescents in New Zealand*), such standards are non-existent for adults.

In summary, as with the 2013 PwC Study *Improving Inflammatory Bowel Disease care across Australia*<sup>62</sup>, there is evidence in New Zealand supporting three key points:

- Prevalence of IBD has markedly increased in recent decades
- Severity of the conditions has worsened
- Onset is most prevalent in the earlier ages of adulthood<sup>63</sup>

An equitable, patient-centred approach is necessary for patient well-being. It also makes sense in terms of managing value-for-money public-health services and care.

The following are the key conclusions of this report.

### 1. New Zealand urgently needs a national IBD registry

There is a clear and urgent need for a national IBD registry so that prevalence and incidence by DHB is fully understood. In conjunction with other research, this will go a long way to improving the understanding of IBD and therefore the effectiveness and bottom line benefit of medical, social and other interventions.

### 2. The current model of care for IBD patients is reactive, inadequate, inconsistent and inequitable

Key shortcomings in the current model of care are the drawn-out diagnostic process, inconsistent and short-term management of the disease and inequitable access to treatment, support and education.

The longer the diagnostic process takes, the worse the outcomes are for the patient in terms of health (physical and psychosocial) and cost burden. It is often not until a patient presents to a hospital's emergency department that they are treated by a gastroenterologist and finally correctly diagnosed. This often lengthy diagnostic period

---

<sup>61</sup> Estimate derived from several regional studies over period 2004 to 2016

<sup>62</sup> PricewaterhouseCoopers, 2013, p. 2

<sup>63</sup> Gibson, 2009. PricewaterhouseCoopers, 2013

is when patients are at the greatest risk of losing their job, lifestyle stability or educational opportunities and being burdened by the many potential costs discussed in this report.<sup>64</sup>

Diagnosis during an acute flare is often the beginning of a pattern of professional contact only during severe episodes of the disease, and patients being left to manage alone while in remission. This is in effect a reactive model of managing the disease; in other words, waiting until the condition is relatively severe before intervening. In the absence of long-term disease management, there is increased risk of ad hoc and unspecialised treatment.

#### *Summary of effects of reactive management of IBD*

- The reactive care model often sees patients become so unwell that they require a much higher level of care to address their flare.
- Disconnected patients may not seek medical attention when a flare begins, which may in turn result in more extreme intervention.
- A lack of regular monitoring means that side effects of medication may not be recognised, interactions with other medications may result in adverse effects for the patient, compliance may become compromised and potential cancers may not be detected as early as they otherwise could be.
- Psychosocial and nutritional health may be neglected.

These effects lead to an increased cost both in quality of life for patients and their families and in financial and other costs to the healthcare system .

### 3. A proactive model of care is needed

The current reactive model of care needs to be replaced with a proactive model, which prevents or at least lessens the impacts of flares. This would include regular monitoring by expert healthcare professionals, which would serve to keep patients informed, supported and motivated to comply with prescribed treatments.

If IBD is proactively managed and the impact of flares is decreased, there will be savings in terms of hospital admissions and avoidable surgeries, and vast improvements in the quality of life of patients.

Further research culminating in clinical guidelines for treating patients with IBD may include investigation into how changes to the current pathways to care could be altered to achieve faster diagnosis and better ongoing care.

For example:

1. How a referral to a specialist could be triggered prior to confirmation of diagnosis
2. The feasibility of interim treatments
3. Utilisation of gastroenterologists as a collective national resource
4. Including pharmacists in a holistic care model as there is an opportunity for checking in when a patient collects their prescriptions

### 4. Pathways and patterns of pharmaceutical treatment vary greatly and timely access to the most efficacious treatments is significantly restricted

There is significant variability in IBD treatment patterns and pathways across the country. The current 'step-up' pyramid approach to prescribing pharmaceutical treatments means that lower cost but potentially less efficacious treatments are used first, with the most expensive medications reserved for those who have failed to respond to treatments at the bottom of the pyramid. If these less efficacious medications are used for long periods of time while uncontrolled inflammation continues, complications could occur, associated with a less favourable long-term prognosis.

The use of more expensive drugs is tightly controlled and patients often have to wait until their disease has reached a very severe state before they can access these treatments.

---

<sup>64</sup> Budgen, 2017



### *Effects of restrictions on availability of pharmaceutical treatments*

- Patients are suffering and may endure continuing uncontrolled inflammation while waiting to qualify for more efficacious treatments.
- Patients who do not respond to anti-TNF $\alpha$  medications, or who lose response over time currently have no other funded treatment options.
- There are inequities among DHBs in prescribing patterns.

## 5. Access to resources and support is currently inequitable.

### *Effects of inequity of access*

Currently, IBD patients who live rurally or who are socio-economically disadvantaged do not have adequate access to IBD specialists.

Those patients who only see specialists when experiencing an acute flare may not get the information they need; they may be too intimidated or may not want to take up the specialist's time by asking questions. This can be dangerous as it may lead to sub-optimal self-care (potentially in terms of medication compliance) or a lack of reporting worsening or new symptoms.

If there is no one to explain the issues and educate the patient or their family in a way that they can understand (and every patient and family is different, as is the impact on their lives), medical and psychosocial outcomes may deteriorate, the risk of stress and distress may increase, and patients may isolate themselves.

A lack of adequate education may lead to patients stopping their medication, thinking that they can manage without, or not understanding the need for medication while in remission.

### *Availability of IBD nurses*

IBD nurses are an invaluable resource to IBD patients, but not enough people have access to one, and children generally don't have access to them at all. The availability of IBD nurses varies significantly among DHBs; while some have them, others do not. In regions where there is no IBD nurse, patients have to navigate (often unsuccessfully) multiple sites and access points for medical imaging, blood tests, pathology testing and prescriptions<sup>65</sup> and tend not to know what support may be available to them.

Considering that, on average, a GP may have only a small number of IBD patients, it is not an efficient solution to propose all GPs become experts in IBD. It should also be noted that not all gastroenterologists specialise in IBD.

**Figure 20** is the currently understood distribution of IBD nurse positions nationally. Depending on where a patient lives, they may or may not have access to a gastroenterologist and/or an IBD nurse.

---

<sup>65</sup> PricewaterhouseCoopers, 2013, p. 9

Figure 20: Current distribution of IBD Nurses

| <b>DHB</b>         | <b>No. IBD Nurses</b> |
|--------------------|-----------------------|
| Auckland           | 4                     |
| Bay of Plenty      | 1                     |
| Canterbury         | 1                     |
| Capital and Coast  | 1                     |
| Hawkes Bay         | 1                     |
| Hutt Valley        | 1                     |
| Lakes              | 1                     |
| Mid Central        | 1                     |
| Nelson-Marlborough | 1                     |
| South Canterbury   | 1                     |
| Southern           | 2                     |
| Taranaki           | 1                     |
| Waikato            | 1                     |
| Waitemata          | 1                     |

Source: CCNZ IBD BOD Workshop 1

It is pertinent to note here that there are no specifically identified and trained paediatric IBD nurses. Furthermore, there is no formal pathway in terms of education and training for nurses to specialise in IBD. All of these issues need to be reviewed and addressed. IBD nurses provide invaluable advice and support to patients and their families and may help to bridge the problematic transition period<sup>66</sup> from paediatric to adult care.

*“IBD impacts children through social isolation as they are unable to attend school or sports and maintain friendships. Friendships are especially hard when the child does not want to talk about what is going on and their friends do not understand what they are going through”*

– CCNZ 2017 Survey

#### Access to IBD specialists

Consultation and surveying carried out for this study revealed a need for more IBD specialists across the country. Research should be undertaken to understand how many more positions would be optimal and where they should be based. This echoes recommendations from the [Gastroenterology Society of New Zealand’s 2011 report](#) to the Health Workforce New Zealand Board that:

1. Vacant gastroenterologist posts need to be filled, especially in rural areas
2. Approximately 10-15 new posts need to be created.

Their report also recommends that increasing specialist IBD nurse positions and hours is included in this process.<sup>67</sup>

The prevalence of IBD indicates that there needs to be more than a 20% increase in gastroenterology specialist positions to match the recommended workforce benchmarks.<sup>68</sup>

<sup>66</sup> Wright, et al., 2014, p. 490

<sup>67</sup> Gastroenterology Society of New Zealand, 2011, pp. 6-7

<sup>68</sup> Association of Salaried Medical Specialists, 2010, p. 13

### Access to psychosocial support

Currently, most IBD patients lack free access to a psychologist, because IBD is designated by the Ministry of Health as a Non-Communicable Disease (NCD), rather than a Long-Term Condition (LTC). This is particularly surprising given its relatively young average age of onset and the continuation of the condition throughout the patients’ lifetimes. These two factors mean that addressing mental health issues early on is likely to make a major difference to patients’ wellbeing (and their contribution to their families, community and the economy). Moreover, there is a strong evidence base to support the use of psychological interventions in people with IBD.

While patients have the most contact with healthcare professionals during an acute flare, when the physical aspects of the disease are severe, little attention is paid to a patient’s psychosocial wellbeing. However, a study has shown that Cognitive Behavioural Therapy (a commonly used psychotherapy) improves the quality of life of “in-need” IBD patients<sup>69</sup> and therefore in a proactive care model, counselling or some other form of emotional and mental health support should be made available to all patients.

CCNZ, a charitable trust, is currently filling the gap in terms of support, information, peer-support and advocacy.

*“Inflammatory Bowel Disease is a complex condition best managed by a multidisciplinary team approach.”*

– Australian IBD Standards 2016

## 6. The costs of IBD to New Zealand are significant

The costs of IBD to New Zealand are brought together in **Figure 21**, demonstrating first that the total known or estimated costs are significant and second that the calculations are conservative. Research is required to identify and measure other direct and indirect costs.

Figure 21: Total of Known or Estimated Costs 2016

| Type                                     | Cost                      | \$m            |
|--|---------------------------|----------------|
| D<br>I<br>R<br>E<br>C<br>T               | Hospital Inpatients       | \$ 17          |
|  | Pharmaceuticals           | \$ 29          |
|  | General Practices         | Needs research |
|  | Patient & Caregiver Costs | \$ 37          |
|  | Emergency Department      | Needs research |
|  | Outpatients               | Needs research |
|  | Mental Health Services    | Needs research |
| I<br>N<br>D<br>I<br>R<br>E<br>C<br>T     | Private Medical Care      | Needs research |
|  | Absenteeism               | \$ 86          |
|  | Presenteeism              | \$ 52          |
|  | Loss of Employment        | \$ 16          |
|  | Welfare Costs             | \$ 8           |
|  | Future Lost Productivity  | Needs research |
|  | Lost Tax Revenue          | Needs research |
|  | Premature Death           | Needs research |
| <b>Total of Known or Estimated Costs</b> |                           | <b>\$ 245</b>  |

*Note: A further cost to include in future studies would be Deadweight Loss, which is the cost of raising tax payer revenue, loss of procurement and consumer surplus.*

*Source: Direct & Indirect Cost sections of this report*

<sup>69</sup> Andrews, et al, 2015, p. 1

## Recommendations

The overarching conclusion of this report is that a significant change of thinking is needed on how IBD is prioritised and treated. The evidence presented here makes it clear that IBD is a disease of growing national significance, and that its increasing scale and cost, and the impact it has on patients' lives, make a rethink of IBD management an imperative.

This report is not calling for a major boost in funding for IBD treatment. Indeed, any additional funding that might be required to meet the costs of earlier diagnosis and potentially more costly initial therapies and/or pharmaceutical interventions, are likely to be offset by savings in healthcare costs and increases in productivity. Furthermore, it is likely, over time, that many of the current costs of IBD could actually be lowered, rather than continue to increase.

Accordingly, it is recommended that CCNZ seek support and resources to achieve the following:

1. Development of a national IBD registry
2. Formal classification of IBD as a Long-Term Condition
3. Development of a New Zealand Standard of Care for IBD patients, reflecting a proactive model of care that addresses current shortcomings in diagnosis, access to treatment and standards of care
4. Measures to ensure adequate nationwide availability of and access to IBD specialists, including:
  - IBD gastroenterologists
  - Trained IBD nurses
  - Psychosocial therapists and support services with IBD experience and training
5. Development of up-to-date, comprehensive information on IBD including diagnostic and treatment guidelines for dissemination across the health sector, in particular to GPs, DHBs, and national health planners
6. A national information campaign on the key facts about IBD, to promote greater understanding, care and support for IBD patients

Practicable proposals for implementing these recommendations are set out in the following chapter, 'Next Steps'

## 7. Next Steps

---

### Overview

This study has found sufficient evidence for some immediate actions, in particular the steps that need to be taken to improve national access to care. Implementing these will require leadership, government and cross-sector support and alignment, and commitment to a work programme underpinned by high-quality, nationwide research. The key actions are listed below.

### 1. Establish an IBD National Care Working Group

#### *Role*

The role of this group would be to address the implications of this study by initiating, guiding and overseeing:

- the research programme (outlined below)
- development of public information and health sector communications plans
- development of a NZ Standard of Care Model
- establishment of IBD nursing as a discipline in its own right, with a formal training regime
- implementation of appropriate, accessible care nationwide.

#### *Membership*

The group should include members from:

- Colorectal Surgical Society of Australia and New Zealand
- Crohn's & Colitis New Zealand
- Dietitians NZ
- New Zealand College of Pharmacists
- New Zealand Nurses Organisation Gastroenterology Nurses' College
- New Zealand Paediatric Gastroenterology Clinical Network
- New Zealand Society of Gastroenterology
- Royal New Zealand College of General Practitioners
- Representatives from Obstetrics and Mental Health

### 2. Initiate a research programme

#### *Objectives*

This BOD study is the initial step in examining the nationwide impact of IBD. It highlights the growing scale and burden of IBD in New Zealand and describes the transformation that could take place through better access to appropriate care for IBD.

IBD experts wish to further improve the potential for earlier diagnosis. This means research to gain a better understanding of the presenting signs and symptoms of IBD so there could be both earlier diagnosis and consequently earlier and more effective interventions.

The research can then be the basis for a holistic care model underpinning the development of Guidelines for a New Zealand Standard of Care for IBD Patients. This research aim is consistent with the Health Research Council's priority to fund transactional and transformational research that has the potential to improve health outcomes and delivery of healthcare and to produce economic gains for New Zealand.<sup>70</sup>

---

<sup>70</sup> Health Research Council of New Zealand, 2017

A potential source of research funding, therefore, is the Health Research Council's Programme Funding, granted over five years.

*The programme objectives would be the following:*

1. Construct a nation-wide evidence base, including
  - a. establishment of an accurate nationwide prevalence rate with a mechanism for routinely monitoring and reporting, and
  - b. gaining a better understanding of the determinants of IBD resulting in earlier diagnosis
2. Draw on this evidence base to:
  - a. develop a nationally consistent response for the improvement of IBD care, including specification of the pathways of care for IBD that maximise patient wellbeing while reducing direct health care costs, and indirect and economic costs
  - b. propose a framework for a proactive, coordinated, holistic care model which would result in the formalisation of Guidelines for a New Zealand Standard of Care for IBD Patients
  - c. identify the number of additional IBD gastroenterology and nursing positions required to meet needs across the country and recommend a strategy for filling these positions, and
  - d. oversee development of a formal training programme for IBD nurses
3. Use the New Zealand population of IBD cases as a basis for a clinical trial investigating the impact of the timing of pharmaceutical interventions, and
4. Calculate DALYs and QALYs for IBD as a basis for considering whether IBD be afforded the priority that is given by the Ministry of Health to other Long-Term Conditions

## Benefits of the research programme

### *Financial savings*

*A reduction in hospitalisation* In clinical practice, a coordinated, multidisciplinary model of IBD care has been shown to reduce health system costs due to a reduction in admissions and bed days through a combination of timely treatment and education.

A study performed in South Australia (SA) in 2011 aimed to find out if introducing a formal IBD service would lead to a reduction in hospitalisation. They did this by comparing the hospitalisation of IBD patients with non-IBD patients, both before and after introducing the service.

They found that the mean number of admissions saved per patient was as high as 40%, with admissions resulting from the emergency department dropping by 10% in the study time frame. The mean cumulative total length of stay for the SA cohort studied in the period prior to and after the change in the care model dropped from 15.37 days to 5.38 days.<sup>71</sup>

If broadly similar results were to be obtained in New Zealand and translated in savings across the country, then total annual (2016) hospitalisation savings of up to \$11 million are possible. If half the improvement seen in South Australia is achieved in New Zealand, then total annual hospitalisation savings of around \$5.6 million are possible. Refer to Appendix B for more details.

---

<sup>71</sup> Sack, *et al*, 2011, p. 4

*Productivity gains* The effects of reduced healthcare utilisation due to a formalised and multidisciplinary approach to IBD care that flow on to all other cost burdens associated with IBD are:

- more time at work
- less time off work for parents or other carers of children
- more productive time while at work
- subsequent clinical interventions become fewer, and
- reduced out-of-pocket expenses.

Modelling of IBD-caused, employment-related indirect costs in Section 4 of this report has estimated that productivity losses from New Zealand GDP in 2016 were likely to be between a low scenario of \$115 million and a high of \$212 million.

If the key drivers of this productivity loss were each improved by 20%, the estimated IBD-caused, employment-related loss to New Zealand GDP would be reduced by between \$27 million and \$60 million per annum. Refer to Appendix C for more details.

There would be other consequent cost reductions as well. Furthermore, failure to seek per capita productivity gains will leave the country exposed, as both the prevalence and incidence of IBD continue to rise, fuelling further cost increases and productivity losses.

### *Better quality of life for patients and their families*

*A coordinated approach to care* Quality coordinated care for patients with IBD not only decreases healthcare utilisation and therefore cost to the health system, patients and their families, but also results in better outcomes for patients in terms of quality of life.

Having access to specialist health professionals means that a patient can be better educated and supported both to cope with their illness and minimise its impacts.

An example of this is having an IBD nurse to help connect the patient to the various specialists they may need to see. An IBD nurse can be a friendly, helpful ally in navigating the often confusing, seemingly labyrinthine public health system.

In keeping with a biopsychosocial approach, a coordinated, proactive model allows for a more holistic approach to care in which the following can be addressed to achieve a better quality of life for IBD patients and their families:

- Psychosocial burden of chronic disease
- Psychological comorbidities
- Potential comorbidity with functional gastrointestinal disorders
- Monitoring and compliance
- Surveillance of associated risks for early detection of cancer
- Sexuality, fertility, family planning and pregnancy
- Iron deficiency and anaemia<sup>72</sup>

Such an approach would also ease stress and lessen the impact of the disease through:

- A more streamlined and easier to navigate patient journey
- Reduced hospitalisations
- Clearing confusion and making resources more accessible

---

<sup>72</sup> Pricewaterhouse Coopers, 2013, p. 17

*Equitable access to education and support* It is important that people with IBD have access to education and support for managing their disease. Younger patients in particular<sup>73</sup> want information so that they can participate in activities while managing their disease. Women need information when considering planning a pregnancy, in order to know what medications are safe to take while pregnant and what the potential risks may be.

It is paramount that all patients understand the function of the medication they are taking, the need for close monitoring for side effects, and the importance of continuing them when they are in clinical remission. Not understanding this may cause patients to stop taking their medication, which could lead to unnecessary flares and complications.

Having access to an IBD nurse is invaluable to personalise education. Studies show that patients respond more positively to a nurse talking with them about medication prescribed than reading a brochure or other printed material.<sup>74</sup> This humanised support serves to empower patients to take control of the management of their disease and is likely to improve both intentional and unintentional non-adherence leading to an increase in adherence to prescribed treatments.

### 3. Develop public and health sector information and communication plans

It is recommended that the following resources be developed and distributed:

- a communication plan to share the knowledge base about IBD across DHBs and Primary Health Organisations (PHOs) to ensure early and accurate diagnosis of IBD followed by appropriate treatment
- a body of work to ensure that first responders, be they GPs, paediatricians, nurses or mental health counsellors, know enough to consider and initiate timely investigations to identify IBD in their patients
- information for primary care practitioners about who to approach for advice and where to send their patients for appropriate expert treatment, irrespective of where they practise in New Zealand, and
- a national public information campaign to promote informed public discussion about IBD and greater understanding, care and support for IBD patients.

---

<sup>73</sup> Yoo, 2015, p. 455

<sup>74</sup> Norton & Kamm, 2002, p. 334



## Appendix A – Epidemiology Methodology & Assumptions

---

There are no New Zealand-wide studies of IBD prevalence or incidence. This 2017 New Zealand IBD Burden of Disease study drew on robust studies and estimates carried out over the last 16 years within specific DHB regions. It then applies broad-brush techniques to estimate the NZ IBD prevalence and incidence.

It is stressed that the results are merely indicative estimates of the prevalence and incidence of IBD in New Zealand and that additional research and deeper analysis of existing data would result in more accurate figures.

Similarly, other methods could have been used, including depicting the prevalence and incidence within a range. However due to the underlying data used and extrapolations and assumptions needed, in an environment with potentially compensating errors, this would not necessarily have presented a more ‘accurate’ picture. All methods would rely on publications that are old, not as detailed as the original Gearry report, and from single geographic areas which even together cover only a small portion of New Zealand’s population.

By relying on a small number of regional studies which constitute a fraction of the 20 DHBs, the estimated New Zealand prevalence and incidence will be biased towards the results from those DHBs or clinicians who have collected and published data.

A significant assumption is made that the single prevalence study in 2004, whilst published and robustly conducted, is a representation of the wider national IBD population at that time. This assumption was made in discussion with the IBD Working Group, and in recognition that it is both robust and the only study from that time. This should be taken into consideration when considering estimated prevalence growth, and future projected growth.

In plain English, this report uses a ‘keep it simple’ approach to work out estimates which are reasonable, given the lack of data available. The actual prevalence could realistically be either below or above the figure presented.

### Prevalence

The following steps were taken (**Figure 22**):

1. Take the existing regionally based IBD studies and estimates, and divide them into two ‘data points’; 2004 and 2016.
2. Assume that the population growth of New Zealand across the period of the recent studies in the second data point is of no great significance as it is within the bounds of other compensating errors and therefore figures from the different years can be directly compared.
3. Weight the prevalence figures by the regional population in the region of the study, and obtain a weighted average prevalence.
4. In the absence of other factors identifiable and/or quantifiable within the scope of this study, assume that these prevalence data points apply to the New Zealand population as indications of the true New Zealand diagnosed prevalence of IBD. The term ‘diagnosed prevalence’, whilst maybe an oxymoron, is used to clearly distinguish clinically established prevalence, as at any one time there appears to be a significant undiagnosed IBD population.<sup>75</sup>
5. Apply the estimated diagnosed New Zealand-wide prevalence to DHB regional populations, using 2006 Census population data. This has been done to illustrate the possible IBD populations within DHB areas (**Figure 23**)

---

<sup>75</sup> CCNZ Survey, 2017

Figure 22: Weighted Average NZ Prevalence, using 2 data points

| Study Short Name  | Study Prevalence | DHB Population at that time | Weighted Prevalence | NZ Population at the time | Estimated Diagnosed NZ IBD Population | Note          |
|---|------------------|-----------------------------|---------------------|---------------------------|---------------------------------------|---------------|
| 2004 Canterbury Gearry  | 308.2            |                             | 308.2               | 4,027,503                 | 12,413                                |               |
| 2012 Nelson Kemp  | 451.6            | 147,210                     | 440.9               | 4,715,555                 | 20,792                                | Taken as 2016 |
| 2016 Wairarapa Stein  | 375.0            | 43,890                      |                     |                           |                                       |               |
| 2016 Hutt Valley Stein  | 450.0            | 145,310                     |                     |                           |                                       |               |
| Prevalence = Cases of IBD per 100,000 people  |                  |                             |                     |                           |                                       |               |
| Est. increase in diagnosed prevalence in NZ over period 2004 to 2016:                         |                  |                             |                     |                           | 67.5%                                 |               |
| Est. per annum straight-line increase in diagnosed prevalence in NZ over period 2004 to 2016: |                  |                             |                     |                           | 5.6%                                  |               |
| Convert to 1 in xxx people  |                  |                             |                     |                           | 227                                   |               |

Source: Multiple referenced studies and submissions<sup>76 77 78 79</sup>

Figure 23: Estimated Prevalence - 2004 and 2016

| DHB                                      | Point 1 - 2004   |                           | Point 2 - 2016   |                           |
|--|------------------|---------------------------|------------------|---------------------------|
|  | Pop. 2006        | Est. Diagnosed Prevalence | Pop. 2016        | Est. Diagnosed Prevalence |
| Auckland District Health Board           | 404,619          | 1,247                     | 510,450          | 2,251                     |
| Bay of Plenty District Health Board      | 194,931          | 601                       | 226,530          | 999                       |
| Canterbury District Health Board         | 466,407          | 1,437                     | 543,820          | 2,398                     |
| Capital and Coast District Health Board  | 266,658          | 822                       | 307,250          | 1,355                     |
| Counties Manukau District Health Board   | 433,086          | 1,335                     | 541,080          | 2,386                     |
| Hawkes Bay District Health Board         | 148,248          | 457                       | 161,780          | 713                       |
| Hutt Valley District Health Board        | 136,101          | 419                       | 145,310          | 641                       |
| Lakes District Health Board              | 98,319           | 303                       | 105,170          | 464                       |
| Mid Central District Health Board        | 158,841          | 490                       | 174,340          | 769                       |
| Nelson-Marlborough District Health Board | 130,062          | 401                       | 147,210          | 649                       |
| Northland District Health Board          | 148,440          | 457                       | 170,560          | 752                       |
| South Canterbury District Health Board   | 53,877           | 166                       | 59,210           | 261                       |
| Southern District Health Board           | 286,224          | 882                       | 319,200          | 1,407                     |
| Tairāwhiti District Health Board         | 44,463           | 137                       | 47,680           | 210                       |
| Taranaki District Health Board           | 104,277          | 321                       | 118,110          | 521                       |
| Waikato District Health Board            | 339,189          | 1,045                     | 400,820          | 1,767                     |
| Wairarapa District Health Board          | 38,613           | 119                       | 43,890           | 194                       |
| Waitemata District Health Board          | 481,611          | 1,484                     | 597,510          | 2,635                     |
| West Coast District Health Board         | 31,329           | 97                        | 33,190           | 146                       |
| Whanganui District Health Board          | 62,208           | 192                       | 62,445           | 275                       |
| <b>TOTALS</b>                            | <b>4,027,503</b> | <b>12,413</b>             | <b>4,715,555</b> | <b>20,792</b>             |

Source: DHB population denominators for 2004 and 2016 were extrapolated from census populations in 2006 and 2013 (Statistics NZ)

<sup>76</sup> Study Short Name – Canterbury Gearry, 2004

<sup>77</sup> Study Short Name – Nelson Kemp, 2012

<sup>78</sup> Study Short Name – Wairarapa Stein, 2016

<sup>79</sup> Study Short Name – Hutt Valley Stein, 2016

## Incidence

Like the method for prevalence, the incidence rate was taken as two data-points, based on regional studies conducted and then converted by weighted average to an estimated New Zealand incidence (**Figure 24**). Also like prevalence, a key assumption from necessity is that the regions for which data exists are representative of the wider national IBD population.

Figure 24: Estimated 2016 NZ Incidence <sup>80 81 82 83 84 85</sup>

| Weighted average NZ Incidence, using 2 data points   |                 |                            |                    |                           |                           |               |
|--|-----------------|----------------------------|--------------------|---------------------------|---------------------------|---------------|
| Study Short Name   | Study Incidence | DHB Population at the time | Weighted Incidence | NZ Population at the time | Estimated Incidence in NZ | Note          |
| 2001 Nelson Kemp   | 11.7            | 130,062                    | 18.9               | 4,027,503                 | 762                       | Taken as 2003 |
| 2004 Canterbury Gearry   | 25.2            | 466,407                    |                    |                           |                           |               |
| 2004 Otago Schultz   | 11.9            | 286,224                    |                    |                           |                           |               |
| 2012 Nelson Kemp   | 18.9            | 136,995                    | 32.6               | 4,241,718                 | 1,382                     | Taken as 2013 |
| 2012 Otago Schultz   | 27.2            | 297,423                    |                    |                           |                           |               |
| 2014 Canterbury Gupta  | 39.8            | 482,178                    |                    |                           |                           |               |
| Incidence = New cases of IBD per 100,000 people in a year                                      |                 |                            |                    |                           |                           |               |
| Est. increase in incidence in NZ over approximate period 2003 to 2013:                         |                 |                            |                    |                           | 81.4%                     |               |
| Est. per annum straight-line increase in incidence in NZ over approximate period 2003 to 2013: |                 |                            |                    |                           | 8.1%                      |               |
| Incidence taken forward to 2016 at est. historical growth                                      |                 |                            |                    |                           |                           |               |
| 2015 Estimate  |                 |                            | 35.2               |                           |                           |               |
| <b>2016 NZ Incidence Estimate</b>  |                 |                            | <b>38.1</b>        | <b>4,715,555</b>          | <b>1,796</b>              |               |

Source: Multiple previously referenced studies

## Prevalence projections

The prevalence projections were estimated by taking the following key steps:

- Estimating the historical (14 year) annual rate of growth in prevalence
- Estimating the future growth of the New Zealand population from 2017 Statistics New Zealand projections, taking a midpoint of the 95% confidence range and striking an annualised growth rate to achieve that
- Project prevalence forward year by year
- Estimate the number of New Zealanders with IBD in future years, as a compound of IBD prevalence and population growth.

Note: Using historical prevalence to forecast future prevalence makes several large assumptions, especially as the 2004 prevalence data point was based on a single regional study. The purpose of the future prevalence projections therefore is to help the reader understand what is possible when considering the burden of this disease. Consideration was given to using incidence to calculate future prevalence projections, however this method also has its drawbacks.

<sup>80</sup> Study Short Name – Nelson Kemp, 2001

<sup>81</sup> Study Short Name – Canterbury Gearry, 2004

<sup>82</sup> Study Short Name – Otago Schultz, 2004

<sup>83</sup> Study Short Name – Nelson Kemp, 2012

<sup>84</sup> Study Short Name – Otago Schultz, 2012

<sup>85</sup> Study Short Name – Canterbury Gupta, 2014

## Appendix B – Direct Costs Methodology & Assumptions

---

Data was obtained for this section from a variety of sources which are noted.

### Hospital admissions

*Admissions* This descriptive analysis was performed on a complete anonymised set of national admissions (taken from the 'National Minimum Dataset') with a principal diagnosis of 'Crohn's disease' coded as ICD10 AN11 K50.xx covering the period July 1, 2001 to June 30, 2013.

Admissions were stratified by treatment groups based on ICD10-AM11 procedure codes obtained from the Ministry of Health. There can be multiple procedure codes for each admission, therefore rules are required to prioritize procedure codes in order to define groups of admissions amenable to analysis. We took into account the first 3 procedure codes, which was sufficient for most of the admissions. The prioritisation rules were: Infusion/injection >Surgical treatment >Medical treatment.

Infusion/injection of a therapeutic agent (ICD10 AM 11, procedure code 9219300) with or without procedure codes received the highest priority in order to highlight secular trends in infusions of pharmaceuticals including infliximab, particularly for day stays. Other admissions without procedure codes were coded as 'medical.' Selected procedure codes including packed red cell transfusions, injections and others were also coded as 'medical'. Admissions with any form of imaging were coded as either 'surgical' or 'medical' depending on the associated procedure codes. Allied health interventions were coded as medical admissions unless they had associated infusion or surgical codes. Day stays were defined as admissions with zero length of stay.

*Years and demographic adjustments.* A financial year (FY) starts on July 1 and ends on June 30 and is indicated in graphs as the year in which the analysis started.

*Admission costs* Costs were derived by multiplying the Case-mix funded cost weight for each admission by the national price in FY2014/15 (\$4682). This expresses all costs in 2014/15 dollar values for comparison. For example, an admission with a cost weight of 2.0 in 2006 would be assigned the national price of  $2 \times \$4682 = \$9364$ . Cost weights include hospital pharmacy costs, which are important when new biological agents are utilised.

Costs exclude brief Emergency Department presentations (<3 hours), which are not available for the period under consideration. Outpatient clinics were not included because adequate patient level information was not available. Thirty admissions with length of stay >90 days were excluded to avoid biasing the analyses of cost.

### Hospital inpatients

The data for this section was provided by Ministry of Health in the form of a summary of discharges and estimated total costs for codes K50 and K51 in the 2015/16 year.

**Figure 25** on the next page, lists all the DRG codes on which data was obtained, sorted by estimated total cost.

Figure 25: IBD-Related Diagnosis Related Groups with Cost and Discharge Data

|  | Discharges (No. of Patients) | Average Length of Stay (Days) | Est. Average Cost | Est. Total Cost      |
|--|------------------------------|-------------------------------|-------------------|----------------------|
| G64B Inflammatory Bowel Disease W/O CC   | 4,155                        | 0.3                           | \$ 2,238          | \$ 9,298,463         |
| G02A Major Small and Large Bowel Procedures W Catastrophic CC                      | 67                           | 17.8                          | \$ 25,213         | \$ 1,689,284         |
| G02B Major Small and Large Bowel Procedures W/O Catastrophic CC                    | 112                          | 9                             | \$ 13,430         | \$ 1,504,106         |
| G48B Colonoscopy W/O Catastrophic or Severe CC                                     | 215                          | 5.1                           | \$ 4,925          | \$ 1,058,786         |
| G64A Inflammatory Bowel Disease W CC   | 215                          | 3.7                           | \$ 4,345          | \$ 934,198           |
| G48A Colonoscopy W Catastrophic or Severe CC                                       | 67                           | 8.3                           | \$ 8,954          | \$ 599,939           |
| G46B Complex Gastroscopy W/O Catastrophic CC                                       | 48                           | 6                             | \$ 6,733          | \$ 323,164           |
| G01B Rectal Resection W/O Catastrophic CC  | 14                           | 8.1                           | \$ 18,892         | \$ 264,485           |
| G01A Rectal Resection W Catastrophic CC  | 10                           | 12.4                          | \$ 25,649         | \$ 256,490           |
| G11Z Anal and Stomal Procedures  | 22                           | 3.7                           | \$ 5,011          | \$ 110,241           |
| A06B Trach W Vent >95 hours W/O Cat CC or Trach/Vent >95 hours W Cat CC            | 1                            | 59                            | \$ 100,968        | \$ 100,968           |
| G47B Other Gastroscopy W/O Catastrophic CC   | 21                           | 5                             | \$ 4,616          | \$ 96,934            |
| G48C Colonoscopy, Sameday  | 32                           | 0                             | \$ 2,323          | \$ 74,338            |
| G46C Complex Gastroscopy, Sameday  | 32                           | 0                             | \$ 2,299          | \$ 73,562            |
| G12C Other Digestive System OR Procedures W/O CC                                   | 11                           | 2.8                           | \$ 6,022          | \$ 66,245            |
| G04B Peritoneal Adhesiolysis W Severe or Moderate CC                               | 5                            | 10.8                          | \$ 13,073         | \$ 65,365            |
| G04A Peritoneal Adhesiolysis W Catastrophic CC                                     | 3                            | 15                            | \$ 20,601         | \$ 61,803            |
| G47A Other Gastroscopy W Catastrophic CC   | 3                            | 25.7                          | \$ 15,705         | \$ 47,115            |
| G12A Other Digestive System OR Procedures W Catastrophic CC                        | 2                            | 21                            | \$ 21,824         | \$ 43,648            |
| G12B Other Digestive System OR Procedures W Severe or Moderate CC                  | 5                            | 6.6                           | \$ 8,306          | \$ 41,531            |
| G05B Minor Small and Large Bowel Procedures W Severe or Moderate CC                | 4                            | 6                             | \$ 9,750          | \$ 39,001            |
| G46A Complex Gastroscopy W Catastrophic CC   | 1                            | 32                            | \$ 28,988         | \$ 28,988            |
| G07B Appendicectomy W/O Malignancy or Peritonitis W/O Cat or Sev CC                | 5                            | 1                             | \$ 5,687          | \$ 28,436            |
| G05C Minor Small and Large Bowel Procedures W/O CC                                 | 4                            | 5.8                           | \$ 7,087          | \$ 28,350            |
| G04C Peritoneal Adhesiolysis W/O CC  | 3                            | 4.3                           | \$ 7,884          | \$ 23,651            |
| G07A Appendicectomy W Malignancy or Peritonitis or W Catastrophic or Severe CC     | 2                            | 3.5                           | \$ 8,729          | \$ 17,458            |
| B82C Chronic and Unspecified Paraplegia/Quadriplegia W or W/O OR Pr W/O Cat/Sev CC | 2                            | 4                             | \$ 7,821          | \$ 15,642            |
| B82B Chronic and Unspecified Paraplegia/Quadriplegia W or W/O OR Procs W Severe CC | 1                            | 2                             | \$ 8,097          | \$ 8,097             |
| 801C OR Procedures Unrelated to Principal Diagnosis W/O CC                         | 1                            | 0                             | \$ 5,234          | \$ 5,234             |
| G47C Other Gastroscopy, Sameday  | 1                            | 0                             | \$ 2,001          | \$ 2,001             |
| P67D Neonate, AdmWt >2499 g W/O Significant OR Procedure W/O Problem               | 1                            | 0                             | \$ 364            | \$ 364               |
| <b>TOTAL IBD DISCHARGES K50-K51 CASEMIX FUNDED</b>                                 | <b>5,065</b>                 |                               |                   | <b>\$ 16,907,890</b> |

Source: Ministry of Health summary for estimated IBD Casemix discharges and costs

### Possible hospitalisation savings based on South Australian data

The table in **Figure 26** below illustrates the possible hospitalisation cost savings used in Section 6, based on the South Australian study cited. The estimates assume that:

- 1 in 20 New Zealanders with IBD hospitalised in a year are admitted for a second time within that year. The South Australian study found that patient admissions were reduced by up to 40%. Hence very simply, discharges in New Zealand may be reduced by 5% of 40%. This assumption is necessary as the casemix data available to this study does not record how many times an individual was hospitalised or across what periods.
- Savings in hospitalisation costs are directly related to length of time in hospital. This assumption is necessary as the breakdown of costs within a hospital stay are not available to this study.

The first scenario models savings if equivalent results are obtained, whilst the second scenario models savings if around half the level of results are obtained in New Zealand.

Figure 26: Possible Savings from Introduction of Formal IBD Service

|                                 | Baseline      | 1) South Australia (Equivalent Results) |              |               | 2) South Australia (Lesser Results) |               |              |
|---------------------------------|---------------|---|--------------|---------------|-------------------------------------|---------------|--------------|
|                                 | NZ 2015/16    | Difference                              | Costs        | Savings       | Difference                          | Costs         | Savings      |
| Discharges*                     | 5,065         | -2%                                     | 4,964        |               | -1%                                 | 5,014         |              |
| Est. Average Cost per patient** | \$ 3,338.18   | -65%                                    | 1,168        |               | -32.5%                              | 2,253         |              |
| Est. Total Casemix Cost         | \$ 16,907,890 |   | \$ 5,799,945 | \$ 11,107,945 |                                     | \$ 11,298,698 | \$ 5,609,193 |

\* Assumes that of the patients hospitalised, 1 in 20 of them are hospitalised more than once

\*\* Assumes % reduction in ALOS = % reduction in costs

Source: Data from MoH discharges 2015/16, modelled on South Australian study

## Appendix C – Indirect Costs Methodology & Assumptions

---

There were no previous studies of this nature to call on. As there was no New Zealand data available, some use was made of overseas data.

It was not within the scope of this study to conduct or commission primary research. One exception was made, however, to carry out a short non-scientific survey of members of CCNZ. This provided some guidance on the quantum of key data which was then used, in conjunction with robust prevalence and statistical data, to give estimations of indirect costs.

The reader should therefore keep in mind that the indirect costs estimated are indications only for giving decision makers a better understanding of the burden of IBD in New Zealand. The sources of data and the methods used by their authors have their own errors. The numerical analysis conducted for this report is concerned not with obtaining accurate answers, nor with modelling in any great depth. It is concerned with obtaining approximate solutions whilst maintaining reasonable bounds on errors.

### Employment-related costs to national productivity

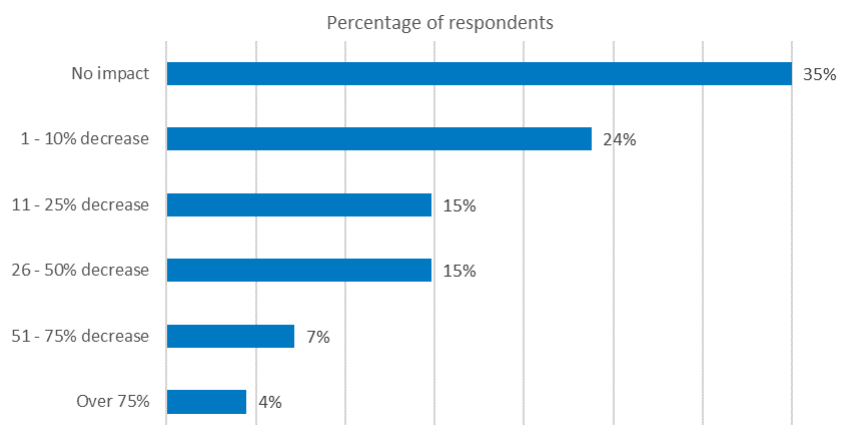
These figures represent the estimated cost to New Zealand GDP, as a measure of production, of the key indirect costs of IBD.

*Absenteeism* - The method used was to estimate the total number of lost work days in the population of people with IBD using the results from the 2017 survey and then convert this to a GDP (NZ\$ 2016) figure based on Treasury and Census data and estimated New Zealand IBD prevalence. To this was added an estimation of the management cost of absenteeism, as this is significant. This figure therefore approximates the GDP lost to New Zealand due to people with IBD being absent from work due to IBD.

*Management Cost* – The cost of absenteeism is not just the lost productivity of the worker; it is also the additional management time needed to manage the effect of the absentee. The ‘Wellness in the Workplace’ surveys estimate this as an average across New Zealand of 30 minutes of management time for each day a staff member is absent.

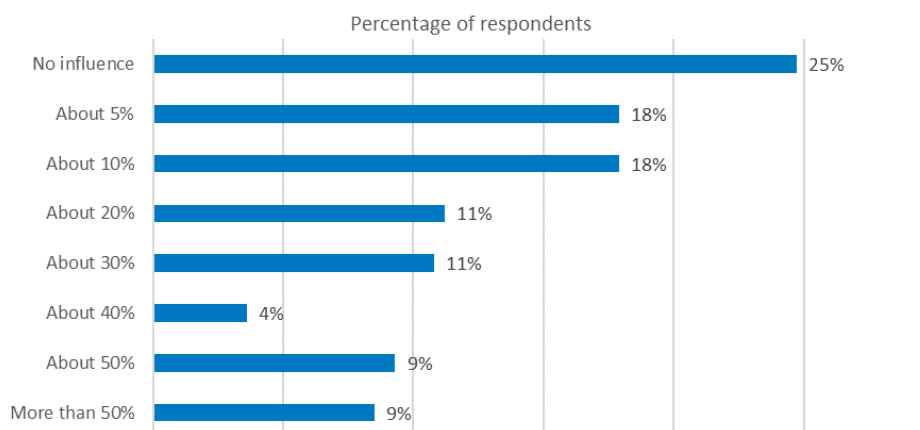
*Presenteeism* – The method used was to estimate the total loss of productivity in the population of people with IBD due to presenteeism using responses from the CCNZ 2017 survey. This considered two factors: when the person was at work, on what percentage of days did they feel their productivity was impaired by their IBD (**Figure 27**); and when they felt they were impaired, to what percentage degree did they feel their productivity was reduced (**Figure 28**)?

Figure 27: Decrease in Productivity while at Work and Affected by IBD



Source: CCNZ Survey 2017 (n=219)

Figure 28: Percentage of Days where IBD Affects Productivity Whilst at Work



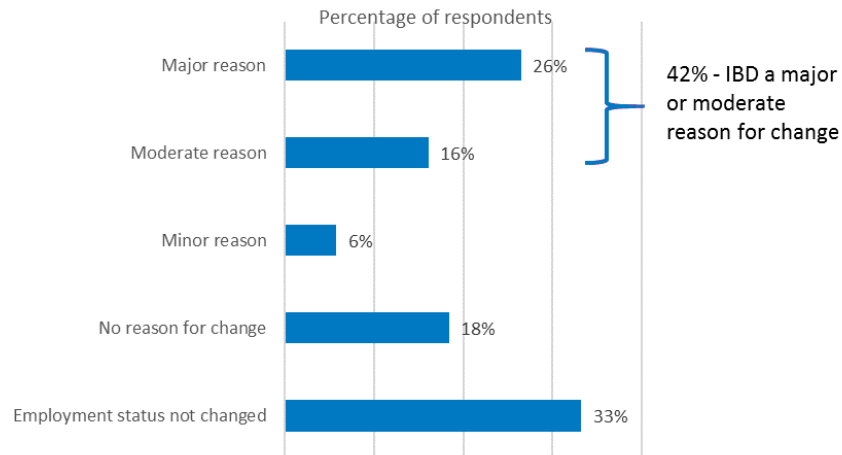
Source: CCNZ Survey 2017 (n=219)

These losses were then converted to a GDP (NZ\$ 2016) figure using Treasury and Census data for GDP and New Zealand population. This figure then, approximates the GDP lost to New Zealand due to people with IBD being less than normally productive whilst at work.

**Loss of Employment** – The method used was to estimate the total loss of productivity caused by people whose employment status was affected by IBD. It considered those respondents to a 2017 survey who reported their employment status had changed and that this change was either “Moderately” or “Majorly” due to their or their dependent’s IBD (Figure 29).



Figure 29: Impact IBD had on Change in Employment Status



Source: CCNZ Survey 2017 (n=219)

The estimated incidence rate for 2016 was multiplied by the percentage of respondents who had lost full time employment, and by the percentage who reported that this loss was due majorly or moderately to their or their dependent’s IBD. This gave an ‘Incidence multiplier’ which estimated the number of full time positions lost in a year due to IBD. A similar calculation was performed for people in part time work, contracting and casual work, except the survey data showed that there was a net gain in this ‘part time’ work.

Finally, these figures were converted to GDP dollars per annum and the net loss from full time employment was reduced by the net gain in part-time employment to arrive at an estimated Loss of Employment figure. A key assumption is that the changes to the person’s employment status lasted for one year. While for some people this would be too much, anecdotally many people with IBD are affected by long term change in their employment status.

### Modelling possible reductions in employment related productivity losses

The key drivers referred to in Section 6 are:

- **Absenteeism** - Average lost working days per IBD case per year (estimated at 12.5 days currently)
- **Presenteeism**:
  - Average percentage of days on which people with IBD in employment are affected by their IBD (estimated currently to be 18.2% of working days)
  - Average percentage loss of productivity experienced by people with IBD on days when they are at work and their IBD is affecting their productivity (estimated currently to be 17.9%)
- **Loss of Employment** - A multiplier applied to the incidence rate which models the shift in employment status as a moderate or major result of a person having IBD (currently estimated at a 12.3% loss of full-time employment and a 5.4% gain of part time employment).

The spreadsheet model used allows each of these drivers to have a percentage change applied to its current estimated value. When applied, these changes flow through costing sheets to give an estimated total loss of employment related national productivity due to IBD, expressed in GDP, 2016 dollars.

**Figure 30** shows the estimated loss of GDP in New Zealand for four simple scenarios of improvements to the key drivers; 10%, 20% and 40%, applied to the Medium scenario of Figure 11. For simplicity in this illustration the same improvement percentage has been applied to each of the five key drivers, although they could just as easily be individually set. The purpose of this model is not to predict cost savings from initiatives, but to simply model estimated cost (productivity loss) reductions if improvements to key drivers occur.

Figure 30: Estimated GDP Loss Reduction

|                                       |                 | Current (2016) |                    | 10% Improvement |                    | 20% Improvement |                    | 40% Improvement |                    |
|---------------------------------------|-----------------|----------------|--------------------|-----------------|--------------------|-----------------|--------------------|-----------------|--------------------|
|                                       |                 | Driver value   | Est. GDP Loss, \$m | Driver value    | Est. GDP Loss, \$m | Driver value    | Est. GDP Loss, \$m | Driver Value    | Est. GDP Loss, \$m |
| Absenteeism                           | Days absent     | 12.5           | 86                 | 11.3            | 77                 | 10.0            | 69                 | 7.5             | 52                 |
| Presenteeism                          | % days affected | 18.2%          | 52                 | 16.4%           | 43                 | 14.5%           | 34                 | 10.9%           | 19                 |
|                                       | Degree affected | 17.9%          |                    | 16.1%           |                    | 14.4%           |                    | 10.8%           |                    |
| Loss of Employment                    | Full Time LOSS  | 12.3%          | 16                 | 11.1%           | 14                 | 9.8%            | 12                 | 7.4%            | 9                  |
|                                       | Part Time GAIN  | 5.4%           |                    | 4.9%            |                    | 4.3%            |                    | 3.3%            |                    |
| <b>TOTAL</b>                          |                 |                | <b>154</b>         |                 | <b>134</b>         |                 | <b>115</b>         |                 | <b>80</b>          |
| <b>Saving from Current (2016) \$m</b> |                 |                |                    |                 | <b>20</b>          |                 | <b>39</b>          |                 | <b>74</b>          |

Source: Several data sources, notably CCNZ Survey 2017

## Appendix D – CCNZ Survey Methodology<sup>86</sup> & Selected Results

---

In early 2017, based on questions that arose while carrying out the IBD Burden of Disease Study, CCNZ sent an online survey to its database at the request of the authors of this report. The results are very useful to help bring some additional understanding of the impact of IBD and a voice to the patient.

The data presented was collected between March 28th and April 5th, 2017.

- A total of N=344 people clicked on the link and completed a portion of the survey.
- There were a total of N=207 people who completed the entire survey.
- N=1,139 invitations were sent to individual email addresses.
- The overall response rate was 30%.
- The total completion rate was 18%.
- The data has not been weighted.
- The margin of error based on an IBD population of ~20,000 is between: +/- 5% and +/- 7% at a 95% confidence interval.

The sample comprised of persons who are members of CCNZ and have an email address. Members of CCNZ are patients, caregivers and supporters including gastroenterologists, IBD nurses and colorectal surgeons. The questions asked for the respondents experience with their own IBD, or their dependent's experience if they were a caregiver.

Where averages were calculated, mid-points of ranges (e.g. 10 – 20, midpoint of 15 is used) to create a rudimentary average.

When using the information from this study, the reader needs to be mindful that bias may exist in this survey:

- The respondents were members of CCNZ and not necessarily represent the view of the *entire* IBD population of New Zealand.
- Those most in need of support may be the most likely to have responded

---

<sup>86</sup> Maddie Shannon, April 2017

## Appendix E – References

---

- Abey, J. (2017). *Epidemiology Crohn's Disease*. Decision Resource Group.
- Access Economics. (2007). *The Economic Costs of Crohn's Disease and Ulcerative Colitis*.
- Andrews, J. M., Bampton, P., Esterman, A., Hetzel, D., Hughes, P., & Mikocka-Walus, A. (2015). Cognitive-behavioural therapy has no effect on disease activity but improves quality of life in subgroups of patients with inflammatory bowel disease: a pilot randomised controlled trial. *BMC Gastroenterology*, 15-54.
- Association of Salaried Medical Specialists. (2010). *State of the Specialist Workforce Crisis in New Zealand's Public Hospitals*. Wellington: Association of Salaried Medical Specialists.
- Budgen, C. (2017, April 3). (S. Snively, Interviewer)
- Burisch, J., Jess, T., Matteo, M., & Lakatos, P. L. (2013, May 1). The burden of inflammatory bowel disease in Europe. *Journal of Crohn's and Colitis*, 7(4), 322–337.
- BusinessNZ. (2015). *Wellness in the Workplace Survey 2015*. Wellington: BusinessNZ.
- Canavan, C., & Abrams, K. R. (2007). Meta-analysis: mortality in Crohn's disease. *Alimentary Pharmacology & Therapeutics*, 861-870. doi:10.1111/j.1365-2036.2007.03276.x
- Crohn's & Colitis UK. (2017, April 24). *AZATHIOPRINE AND MERCAPTOPYRINE*. Retrieved from Crohn's & Colitis UK: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)
- Crohn's & Colitis UK. (2017, April 24). *BIOLOGICAL DRUGS*. Retrieved from Crohn's & Colitis UK: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)
- Crohn's & Colitis Australia. (2016). *Australian IBD Standards*. Melbourne.
- Crohn's & Colitis Foundation. (2017, April 24). *Aminosalicylates*. Retrieved from Crohn's & Colitis Foundation: <http://www.crohnscolitisfoundation.org/resources/aminosalicylates.html>
- Crohn's & Colitis Foundation of America. (2009, April). *Managing Flares and Other IBD Symptoms*. New York, United States of America.
- Crohn's & Colitis New Zealand. (2017, March 20). *About Crohn's & Colitis New Zealand*. Retrieved from Crohn's & Colitis New Zealand: <http://www.toiletmap.co.nz/about-crohns-colitis-new-zealand-0>
- Crohn's & Colitis New Zealand. (2017, March 20). *Learn About IBD*. Retrieved from Crohn's & Colitis New Zealand: <http://crohnsandcolitis.org.nz/learn+about+ibd?src=nav>
- Crohn's & Colitis NZ. (2017, May 1). *IBD in Children and Adolescents*. Retrieved from Crohn's & Colitis NZ: <http://crohnsandcolitis.org.nz/IBD+in+Children+and+Adolescents?src=mod-toc>
- Crohn's and Colitis Foundation of Canada. (2012). *FAST FACTS: The Impact of IBD in Canada 2012*. Crohn's and Colitis Foundation of Canada.
- Ellis, P. M., & Collings, S. C. (1997). *Mental Health in New Zealand from a Public Health Perspective*. Wellington: Ministry of Health.

- Forbes, A. (2013). *Mortality in a Cohort of Inflammatory Bowel Disease Patients in Canterbury, New Zealand*. Dunedin: University of Otago.
- Gapasin, J., Van Langenberg, D. R., Holtmann, G., Hetzel, D. J., & Andrews, J. M. (2012). Potentially avoidable surgery in inflammatory bowel disease: what proportion of patients come to resection without optimal preoperative therapy? A guidelines-based audit. *Internal Medicine Journal*, 42(5), e84 - e88. doi:10.1111/j.1445-5994.2010.02328.x
- Gastroenterology Society of New Zealand . (2011). *Report to the Health Workforce New Zealand Board on the Gastroenterology Workforce Service Review* . Wellington: Gastroenterology Society of New Zealand .
- Gearry, R. B., Lea, R. A., Roberts, R. L., Chambers, G. K., Barclay, M. L., & Kennedy, M. A. (2006, April). CARD15 allele frequency differences in New Zealand Maori: ancestry specific susceptibility to Crohn's disease in New Zealand? *Gut*, 55(4), 580. doi:10.1136/gut.2005.085464
- Gearry, R. B., Richardson, A. K., Frampton, C. M., Dodgshun, A. J., & Barclay, M. L. (2010). Population-based cases control study of inflammatory bowel disease risk factors. *Journal of Gastroenterology and Hepatology* , 325–333.
- Gearry, R., Poole, B., Rawlings, H., Worsfold, C., & Wyeth, J. (2010). *Presentation to the Hon. Tony Ryall Minister of Health*.
- Gibson, P. (2009). Overview of Inflammatory Bowel Disease in Australia in the last 30 years. *Journal of Gastroenterology and Hepatology*, S63.
- Harvard School of Public Health. (2017, April 24). *Obesity Prevention Source*. Retrieved from Harvard School of Public Health: <https://www.hsph.harvard.edu/obesity-prevention-source/prevalence-incidence/>
- Health Research Council of New Zealand. (2017, April 23). *Funding Opportunities*. Retrieved from Health Research Council of New Zealand: <http://www.hrc.govt.nz/funding-opportunities>
- Johan Burisch, T. J. (2013). The burden of inflammatory bowel disease in Europe. *Journal of Crohn's and Colitis*, 322–337.
- Kaplan, G. G. (2015). The global burden of IBD: from 2015 to 2025. *Nature Reviews Gastroenterology and Hepatology*, 12, 720–727. doi:10.1038/nrgastro.2015.150
- Knowles, S., & Mikocka-Walus, A. (2015). *Psychological Aspects of Inflammatory Bowel Disease: A Biopsychosocial Approach*. Sussex: Routledge.
- Lion, M., Gearry, R. B., Day, A. S., & Eglinton, T. (2017, May 1). *The cost of paediatric and perianal Crohn's disease in Canterbury, New Zealand*. Retrieved from The New Zealand Medical Journal: <https://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2012/vol-125-no-1349/article-lion>
- Lopez, R. N. (2016). *Paediatric Inflammatory Bowel Disease in New Zealand (PINZ) Study*. Dunedin: University of Otago.
- Mental Health Commission. (2011). *Child and Youth Mental Health and Addictions*. Wellington: Mental Health Commission.

- Milne, R. (2017). *Inflammatory Bowel Disease in New Zealand*. Auckland: University of Auckland.
- Ministry of Health. (2017, April 30). *The New Zealand Casemix System – An Overview*. Retrieved from Ministry of Health: <http://www.health.govt.nz/publication/new-zealand-casemix-system-overview-0>
- Molodecky, N., Soon, I., Rabi, D., Ghali, W., Ferris, M., Chernoff, G., . . . Kaplan, G. (2012, January). Increasing incidence and prevalence of the inflammatory bowel diseases with time, based on systematic review. *Gastroenterology*, 142(1), 46-54. doi:10.1053/j.gastro.2011.10.001.
- Moore, M. (2013). *The Un-Speakability of Problems with Gut Functions: The Taboo of Talking about Poop*. Auckland: University of Auckland.
- Neuendorf, R., Harding, A., Stello, N., Hanes, D., & Wahbeh, H. (2016). Depression and anxiety in patients with Inflammatory Bowel Disease: A Systematic Review. *Journal of Psychosomatic Research*, 70-80.
- Norton, C., & Kamm, M. A. (2002). Specialist nurses in gastroenterology. *Journal of the Royal Society of Medicine*, 331-335.
- Phan, V.-A. H., van Langenberg, D. R., Grafton, R., & Andrews, J. M. (2012). A dedicated inflammatory bowel disease service quantitatively and qualitatively improves outcomes in less than 18 months: a prospective cohort study in a large metropolitan centre. *Frontline Gastroenterology*, 137-142.
- PHARMAC. (2016). *Year in Review*. Wellington: PHARMAC.
- PHARMAC. (2017, March). Inflammatory Bowel Disease - PHARMAC data. Wellington, New Zealand.
- PHARMAC. (2017, March 31). *Schedule*. Retrieved from PAHRMAC: <https://www.pharmac.govt.nz/Schedule>
- Pricewaterhouse Coopers. (2013). *Improving Inflammatory Bowel Disease care across Australia*. Crohn's & Colitis Australia.
- Rubin, D. T. (2015, June). When Should Therapy for Inflammatory Bowel Disease Be Stopped? (G. & Hepatology, Interviewer)
- Sack, C., Phan, V. A., Grafton, R., Holtmann, G., van Langenberg, D. R., Brett, K., . . . Andrews, J. M. (2011). A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease. *Journal of Crohn's and Colitis*. doi:10.1016/j.crohns.2011.08.019
- Scanlen, A. (2017, March 27). (S. Kahui, Interviewer)
- Schultz, M. (2017, March 31). New Zealand.
- Shannon, M. (2017). *The Economic Burden of Disease*. Wellington.
- Simpson, J., Duncanson, M., Oben, G., Adams, J., Wicken, A., Butchard, M., . . . Gallagher, S. (2016). *The Health Status of Children and Young People in the Northern District Health Boards 2015*. University of Otago .
- Statistics New Zealand. (2016). *2014/2015 National Health Survey: Results*.

- Su, H. Y., Gupta, V., & Day, A. S. (2016). Rising Incidence of Inflammatory Bowel Disease in Canterbury, New Zealand . *Inflammatory Bowel Disease*, 1-7.
- Su, H. Y., Gupta, V., S, A., & Geary, R. B. (2016). Rising Incidence of Inflammatory Bowel Disease in Canterbury, New Zealand. *Inflammatory Bowel Disease Journal*, 1-7.
- Tan, M., Holloway, R., Lange, K., & Andrews, J. (2012, July). General practitioners' knowledge of and attitudes to inflammatory bowel disease. *Internal Medicine Journal*, 42(7), 801-807. doi:10.1111/j.1445-5994.2011.02586.x.
- Thomas, G. R., Lewis-Morris, T., Rowbotham, D., Whiteside, C., Joyce, S., Inns, S., . . . Geary, R. B. (2014). Adalimumab for Crohn's disease in New Zealand—a prospective multicentre experience. *The New Zealand Medical Journal* , 23-33.
- Tobias, M. (2016). *Health Loss in New Zealand 1990–2013* . Wellington: Ministry of Health.
- Torres, J., Caprioli, F., Katsanos, K. H., Lobatón, T., Micic, D., Zerôncio, M. V., . . . Colombelk, J.-F. (2016). Predicting Outcomes to Optimize Disease Management in Inflammatory Bowel Diseases. *Journal of Crohn's and Colitis*, 1385-1394.
- U. S. Department of Health and Human Services. (2017, April 24). *Principles of Epidemiology in Public Health Practice. Third Edition. An Introduction to Applied Epidemiology and Biostatistics*. Retrieved from Centres for Disease Control and Prevention: <https://www.cdc.gov/ophss/csels/dsepd/ss1978/lesson3/section2.html>
- van Langenberg, D. R., Simon, S. B., Holtmann, G. J., & Andrews, J. M. (2010). The burden of inpatient costs in inflammatory bowel disease and opportunities to optimize care: A single metropolitan Australian center experience. *Journal of Crohn's and Colitis*, 413-421.
- Wright, E., Williams, J., Andrews, J., Day, A., Geary, R., Bampton, P., . . . De Cruz, P. (2014). Perspectives of paediatric and adult gastroenterologists on transfer and transition care of adolescents with inflammatory bowel disease. *Internal Medicine Journal*, 44(5), 490-496. doi:10.1111/imj.12402.
- Wu, D., Kendall, D., Lunt, H., Willis, J., Darlow, B., & Frampton, C. (2005). Prevalence of Type 1 diabetes in New Zealanders aged 0-24 years. *New Zealand Medical Journal*.
- Wyeth, J. (2017, March 13). Meeting at Pharmac. (S. Kahui, Interviewer)
- Yoo, Y.-S. C.-H.-S. (2015). Disease-Related Knowledge and Information Needs Among Inflammatory Bowel Disease Patients in Korea. *Gastroenterology Nursing*, 455-463.



**Crohn's & Colitis New Zealand Charitable Trust**

P O Box 22280

Khandallah

Wellington 6441

[www.crohnsandcolitis.org.nz](http://www.crohnsandcolitis.org.nz)

ISBN Number: 978-0-473-40073-6